An Applied Behavioral Approach

A CLINICIAN'S GUIDE *to*

HELPING CHILDREN COPE *and* COOPERATE *with* MEDICAL CARE

KEITH J. SLIFER, PH.D.

VISIT…

A Clinician's Guide to Helping Children Cope and Cooperate with Medical Care

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A Clinician's Guide to *Helping Children Cope and Cooperate with Medical Care*

AN APPLIED BEHAVIORAL APPROACH

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Note to the Reader: The discussions and procedures herein are intended to acquaint those providing care for children who are undergoing medical care with some of the behaviors, emotions and practical issues involved in this care giving. It is intended to provide information to help children *in general* and not to help any specific child. The views expressed are not necessarily the views of the author or of the publisher. This book is not meant to substitute for medical or psychological treatment, and treatment should not be based solely on its contents.

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To my son and inspiration, Nicholas John Slifer,
who taught me to laugh aloud and be joyous
in the midst of adversity

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Preface

The purpose of this book is to provide a resource for individuals who care for children with medical conditions. This includes parents and other family caregivers, as well as behavioral, mental health, medical and allied health professionals, paraprofessionals, and students. All of these individuals at one time or another may share the common purpose of helping children be as comfortable as possible in the context of illness, injury, disability, and associated medical treatment.

A fundamental premise of this book is that children can be helped to live more successfully and comfortably with their health conditions when they are taught skills to manage their anxiety and discomforts while also learning to cooperate and cope with the challenges involved in their medical care. Each chapter begins and ends with a summary list of key points to help the reader remember the techniques and apply them.

The book begins with a discussion of the experience of medical care from a child's perspective (chapter 1), followed by a brief presentation of the history of applied behavior analysis and some of its concepts that are most relevant to the pediatric medical context (chapter 2). In chapter 3, some characteristics of medical care and health care settings are discussed in relation to how they impact parent-child interactions and in relation to the behavioral principles introduced in chapter 2.

There is no question that the unique characteristics of child behavior during illness and in the context of medical care often make the behavior especially stressful for parents and medical caregivers. However, parents and caregivers who have a better understanding of general behavior principles and how to apply fundamental techniques of child behavior management can understand and manage their children's challenging behaviors and assist their child in cooperating and coping with health problems and medical care. Fundamentals of general child behavior management are presented in chapter 4.

Subsequent chapters focus on common behavioral challenges that children and their caregivers encounter during specific health care situations. Each chapter will describe the patient group affected and their unique problem or problems, followed by suggested strategies and procedures for assessing difficulties and planning cognitive, behavioral, and environmental interventions. The unique stresses and challenges confronted by family caregivers and health care providers in each situation are discussed along with conceptual and practical ways to help manage these difficulties and empower the caregivers to better understand and assist the affected child. Specific intervention procedures are then presented such that the reader will be able to understand what is needed and either be able to conduct them directly or know how to seek assistance from a professional who can implement these procedures. Each chapter also includes, where appropriate, a brief presentation of important considerations for special patient groups such as those with intellectual and developmental disabilities and/or severe behavior disorders. Finally, the empirical evidence supporting the procedures will be reviewed, and an illustrative case example or examples will be presented.

My hope is that this book will begin to establish a bridge between, on the one hand, care providers who have a strong interest in the coping and adjustment of children and youth during pediatric medical care and, on the other hand, care providers who are dedicated to translating the practical and procedural riches that have arisen from the field of applied behavior analysis into helpful clinical practices.

A Clinician's Guide to Helping Children Cope and Cooperate with Medical Care

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A Child's Experience of Medical Settings and Health Care

IN THIS CHAPTER

- A review of the prevalence of chronic medical conditions in children.
- An overview of the impact of chronic health conditions on children and families.
- A description of the literature on which this book is based.
- A summary of the purpose of this book.

1.1. PATIENT POPULATION AND TARGET PROBLEMS

An estimated 9.3 million children in the United States are receiving treatment for a chronic or recurrent health condition,[1] requiring them to be seen regularly by pediatricians, family medicine practitioners, physician's assistants, nurse specialists, and pediatric subspecialists. The prevalence of chronic conditions in children has an enormous impact on our society, accounting for about 42% of the total medical costs for children in the United States, 66 million restricted activity days, and 27 million days missed from school each year. In addition, having a child with a chronic health condition has been associated with higher rates of marital stress, divorce, parental unemployment, and financial problems.[1] Clearly a significant amount of societal, familial, and personal resources are being devoted to maintaining the often-tenuous grip on health and quality of life held by children with chronic conditions.

The variety of health conditions that afflict children in the twenty-first century is quite large, ranging from the nearly universal experience of childhood immunizations to the relatively rare occurrence of complex congenital

disorders, childhood malignancies, and severe traumatic injuries. For most children, illness, doctors visits, needles, and X-rays make up a very small portion of their childhood. Yet for an unfortunate minority, doctors visits, late-night trips to the emergency department, hospital admissions, anesthesia, surgery, needle sticks, wound cleaning, seizures, nausea, vomiting, pain, and fear are common experiences. These children often know the hospital as well as they know their family home. Most often, these are children who are developing typically in terms of their intellectual and cognitive functioning, but as the number of chronic conditions they have increases, so does their utilization of health services, including those for physical and mental health problems. Furthermore, as chronic health conditions increase, so does the prevalence of developmental and learning disabilities, as well as emotional and behavioral problems.[2] Children with chronic health conditions also are at greater risk of developing severe acute illnesses requiring unanticipated pediatric intensive care unit admissions.[3] These children and their families are often some of the most vulnerable among us. They will be discussed often in the chapters to follow.

1.2. ASSESSING THE PROBLEMS

The primary purpose of this chapter is to help caregivers of children and adolescents with health conditions, including parents or other home caregivers and health care professionals both in practice and in training, to better understand the daily experiences, behavior, emotions, and developmental challenges of children with health conditions. Of course, to understand is an elusive quest. To understand in what context, in relation to what, and unto what end? For some, to understand is to observe, to describe, to predict. For others it is to feel empathy and compassion for the observed. For still others, to "know" or "understand" requires the ability to control or modify the nature of the object of inquiry.

For the purposes of this book, the objective of "understanding" will be to consider how experimentally established principles of conditioning, learning, and behavior as described in the body of scientific literature known variously as behavioral psychology, experimental analysis of behavior, and applied behavior analysis can contribute to the health status, medical experiences, medical care, and quality of life of children with chronic health conditions, their caregivers, and health care providers.

In chapter 2, principles of conditioning, learning, and behavior, which have been hypothesized and applied in clinical care and research on the behavior of children in medical settings, will be discussed in more detail.

1.3. SUPPORTING LITERATURE

Over the past four decades, applied behavior analysis has produced an extensive literature devoted to studying and treating a host of behavior problems that impact individuals and institutions in our society. Only a small portion of this work has addressed concerns of relevance to pediatric health care, but that portion is growing. It is that literature that forms the foundation of this book. This foundation is supplemented with pertinent literature from pediatrics, child clinical psychology, pediatric psychology, and pediatric rehabilitation. In addition, experience and clinical observations from 30 years of practice providing behavioral care to children and families in medical settings are used to supplement the literature discussed and to illustrate the procedures and protocols being presented.

What is it like to be a child with a chronic, complex, and life-threatening illness? What are the daily challenges encountered by their parents, caregivers, siblings, and health care providers? Which children and families will have the greatest distress, most difficulty coping, and greatest resilience, and which will require mental health services? Who will thrive in the hospital, and who will become depressed? Such questions have been asked by psychologists and other social scientists working in academic medical settings. Asking these questions has stimulated the development and proliferation of behavioral and social science studies that have evolved to become the field of pediatric psychology. This field has produced a large literature and knowledge base. The reader is referred to several existing texts and journal articles summarizing the state of the art and science in pediatric psychology.[4–9] Such texts will point the reader to the many fine research articles, clinical reports, and commentaries that have been published in the *Journal of Pediatric Psychology*. The field of pediatric psychology has provided a great deal of research and scholarly work. It has discovered knowledge concerning the child, family, and environmental variables that are associated with distress, coping, vulnerability, and resilience in children with chronic medical conditions. Subtleties of age, ethnicity, family structure, parenting style, caregiver education, and socioeconomic status can help identify children at greatest risk for developing behavioral distress and nonadherence with recommendations. This type of work is

important to intervention planning and behavioral health care service delivery.

It is not the purpose of this book to comprehensively review this outstanding body of literature or the work represented in peer-reviewed journals such as the *Journal of Applied Behavior Analysis* or *Experimental Analysis of Behavior*. I will refer to this valuable literature at times, but I focus on what to do when you have a pediatric patient before you who is unusually distressed, uncooperative, or disruptive. This book acknowledges these resources, which are available and recommended as references to caregivers and practitioners devoted to learning more about how these literatures can improve the behavior and adaptation of children with medical conditions receiving medical care across the continuum of health care settings.

This book has a modest purpose, which is to draw selectively from the above-mentioned resources and from related clinical experiences to describe a conceptual approach and practical protocols for addressing a series of commonly occurring behavioral and emotional challenges encountered by children with chronic health conditions, their caregivers, and allied health professionals. The topics included stem from practical behavior problems encountered by family caregivers and health care professionals when providing medical care and attempting to maintain child adherence to pediatric medical regimens. The overarching goal here is to demonstrate what is possible and can become a part of routine clinical practice. With the assistance of behavioral interventions, children with chronic conditions may live longer, healthier, and better-quality lives and may reach their highest potential, differing as little as possible from their unaffected, typically developing peers.

1.4. ORIGINS OF THE INTERVENTION PROCEDURES

What follows in this book was developed by working clinically with pediatric patients having chronic medical conditions (cerebral palsy, epilepsy, cancer, asthma, congenital abnormalities of the brain, heart, liver, kidneys, pancreas, etc.) and with children undergoing rehabilitation after traumatic injuries or surgery (brain injury, spinal cord injury, orthopedic injuries, strokes, brain tumor resection, hemispherectomy, burns, etc.). The material presented in subsequent chapters was born of clinical necessity, and when relevant published intervention studies were available, it was based on their findings. What has resulted from this work is a growing body of specialized literature describing practical approaches to solving behav-

ioral challenges to coping with and optimally benefitting from modern medical care. This has involved both reduction of problem behaviors and acquisition of new skills by patients and caregivers.

1.5. SPECIAL CONSIDERATIONS AND CHALLENGES

Children with medical conditions require frequent diagnostic and treatment procedures. Many of these will be described in the various chapters that follow. Most of these procedures are uncomfortable in some way, may be frightening and/or painful, and require children to follow adult instructions to hold still (often in uncomfortable positions) and inhibit any behavior that may interfere with the procedure or treatment. Such health care procedures are frequently disliked and avoided by adults who have the capacity and maturity to understand why they are important. In spite of the many unpleasant qualities of medical care and limited comprehension of their condition, symptoms, and the rationale for treatment, children can, and frequently do, learn quickly to cooperate with the care they need. Amazingly, many do this quite naturally with few accommodations beyond what is provided for adults. Some, however, have difficulty coping with the anxiety, discomfort, pain, and movement restriction required for safe and efficient care.

Indeed, there is a vulnerable minority with so much distress that they are unable to cooperate and therefore get less-than-optimal medical care or require sedation or general anesthesia for tests and treatments with which other children are able to cope and cooperate. Health care workers recognize these children because they "fail" their diagnostic tests and are "unable to tolerate" or are "noncompliant" with necessary care. Their behavior disrupts clinics and inpatient units and wreaks havoc with schedules for diagnostic tests. These children often frustrate health care workers, even those with excellent pediatric training and years of pediatric experience. Their parents become distressed and frustrated. While this challenging minority is not the only group of children and youth to which this text applies, it is the group that seems to suffer most emotionally and to demand the most time, resources, and patience from family caregivers and health care professionals. It is this group of most challenging pediatric patients that has inspired the techniques and procedures that are presented in this book. These children have taught us with their behavior what helps them behaviorally and emotionally and what does not. Such children are well known to health care professionals who wish to help them and their families but are at a loss as to how to do so.

I hope that this book will help both family caregivers and health care providers recognize when specialized behavioral interventions are needed. I describe how these interventions can be implemented, so care providers know what they can do to help and what kind of help to request from behaviorally trained therapists. I also describe how to solve practical problems such as getting a distressed child to cooperate with a physical examination. Procedures for teaching motion control for MRI, CT, or other types of diagnostic imaging are presented. Gaining a child's cooperation with uncomfortable medical procedures or medical self-care routines is also covered. Information and techniques are provided that can be used to help a child with intellectual or developmental disabilities tolerate the application of electroencephalogram sensors or wear a respiratory assistance device (positive airway pressure mask). Other topics include teaching a child to swallow pills and improving child and caregiver adherence with oral medication or medical self-care such as tracheostomy cleaning and suctioning, or intermittent self-catheterization.

A variety of medical situations are discussed, and common behavior principles, teaching methods, and clinical approaches are highlighted and applied across situations, medical procedures, and treatments. By the time the reader finishes this text, she or he will have been introduced to basic principles of learning and behavior and will have been shown how these principles can be applied and generalized to numerous pediatric medical situations. If this book fulfills its intended mission, the reader will have learned about the myriad ways in which behavior analysis and therapy can facilitate child and caregiver coping, cooperation, and ability to benefit from medical care without relying on sedation, anesthesia, or restraint for behavior management.

KEY CONCEPTS

- Approximately 9.3 million children in the United States receive treatment for a chronic or recurrent health condition.
- Chronic health conditions are associated with increased risk of developmental, learning, emotional, and behavioral problems, which in turn impact coping with, adherence with, and quality of medical care.
- There is a body of specialized literature describing practical approaches to solving behavioral challenges to coping with and optimally benefitting from modern medical care.

- The roots of this literature are grounded in the scientific principles of conditioning, learning, and behavior.
- This literature needs to be more widely disseminated to family caregivers and professional health care providers.

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Introduction to Applied Behavior Analysis and Behavior Principles

IN THIS CHAPTER

- This chapter is devoted to a brief review of the essential definitions of terms, principles, and standards of evidence on which the assessment and intervention strategies described in subsequent chapters are based.
- These principles, concepts, and procedures have broad generality across the challenging health care situations discussed in the chapters that follow and also apply to many other problems not specifically discussed in this book.

2.1. PATIENT POPULATION AND TARGET PROBLEM(S)

The information in this chapter applies to all populations of patients regardless of age, diagnosis, or developmental level. The chapter is devoted to an introduction of the fundamental terms, principles, and standards of evidence needed to understand and implement assessment and intervention strategies with all of the children, adolescents, young adults, and caregivers described in the remaining chapters.

2.2. ASSESSMENT PROCEDURES

Antecedent Assessment

Antecedent assessment requires direct observation and recording of observational data to assess the environmental conditions and internal physiological states that are most frequently associated with problem behavior and those that are associated with positive behavior. This is initiated by

recording observations on an antecedent-behavior-consequence (ABC) data sheet (see fig. 2.1). Many helpful behavioral interventions involve proactive modification of the social and physical environment, as well as the individual's physiological state, whenever possible, to prevent or minimize the occurrence of excessive distress and other unhelpful behavior, and to increase the probability of appropriate adaptive behavior. The ABC analysis helps to identify potentially controlling variables (social situations, environmental conditions, and physiological states), to generate hypotheses about what motivates behaviors of interest, and to select individual and/or environmental factors or features that might be productively targeted for modification using behavioral and cognitive-behavioral procedures.

Reinforcer Assessment

A reinforcer assessment helps to establish effective consequences for strengthening behavior for any particular individual. Such an assessment may be accomplished by having the primary caregiver indicate the child's preferences on a checklist of potentially reinforcing items and activities for the child's developmental level. Generally speaking, preferred items or activities (those that, if given a choice, the child will seek, select, and use) have the best potential as reinforcers to strengthen desirable behavior. There are many evidence-based approaches to reinforcer assessment, particularly for children with intellectual and developmental disabilities (IDD).[1] The Reinforcer Assessment for Individuals with Severe Disabilities (RAISD)[2] is presented as an example (see fig. 2.2). While this particular assessment was developed specifically for youth with IDD, the general categories are based on prior reinforcer surveys that were developed with adults, adolescents, and typically developing schoolchildren.[3-6]

Task Analysis

A task analysis refers to breaking a complex behavior or task into component steps and then presenting them to the learner one step at a time and documenting how many of the steps can be accomplished before, during, and after formal behavioral intervention. The learner's specific behavioral response to each step is recorded to establish a

A B C Data Sheet			
Child's Name: _____ Date: _____			
Observer: _____ Time of Observation: _____			
Time	Antecedents	Behavior	Consequences

Figure 2.1 Example of an antecedent-behavior-consequence observational data form. Based on work by Bijou, S.W., Peterson, R.F., & Ault, M.H. (1968). A method to integrate descriptive and experimental field studies at the level of data and empirical concepts. *Journal of Applied Behavior Analysis*, *1*, 175–191 (see pp. 178–179).

Student's Name: _____

Date: _____

Recorder: _____

The purpose of this structured interview is to get as much specific information as possible from the informants (e.g., teacher, parent, caregiver) as to what they believe would be useful reinforcers for the student. Therefore, this survey asks about categories of stimuli (e.g., visual, auditory). After the informant has generated a list of preferred stimuli, ask additional probe questions to get more specific information on the student's preferences and the stimulus conditions under which the object or activity is most preferred (e.g., What specific TV shows are his favorite? What does she do when she plays with a mirror? Does she prefer to do this alone or with another person?)

We would like to get some information on _____'s preferences for different items and activities.

1. Some children really enjoy looking at things such as a mirror, bright lights, shiny objects, spinning objects, TV, etc. What are the things you think _____ most likes to watch?

   Response(s) to probe questions:

2. Some children really enjoy different sounds such as listening to music, car sounds, whistles, beeps, sirens, clapping, people singing, etc. What are the things you think _____ most likes to listento?

   Response(s) to probe questions:

3. Some children really enjoy different smells such as perfume, flowers, coffee, pine trees, etc. What are the things you think _____ most likes to smell?

   Response(s) to probe questions:

4. Some children really enjoy certain food or snacks such as ice cream, pizza, juice, graham crackers, McDonald's hamburgers, etc. What are the things you think _____ most likes to eat?

   Response(s) to probe questions:

Figure 2.2 Reinforcer Assessment for Individuals with Severe Disabilities (RAISD). *Source*: Fisher, W.W., Piazza, C.C., Bowman, L.G., & Amari, A. (1996). Integrating caregiver report with a systematic choice assessment. *American Journal on Mental Retardation*, *101*, 15–25. Reprinted with permission from the American Association on Intellectual and Developmental Disabilities. (*Figure 2.2 continued on page 12.*)

5. Some children really enjoy physical play or movement such as being tickled, wrestling, running, dancing, swinging, being pulled on a scooter board, etc. What activities like this do you think _____ most enjoys?

Response(s) to probe questions:

6. Some children really enjoy touching things of different temperatures, cold things like snow or an ice pack, or warm things like a hand warmer or a cup containing hot tea or coffee. What activities like this do you think _____ most enjoys?

Response(s) to probe questions:

7. Some children really enjoy feeling different sensations such as splashing water in a sink, a vibrator against the skin, or the feel of air blown on the face from a fan. What activities like this do you think _____ most enjoys?

Response(s) to probe questions:

8. Some children really enjoy it when others give them attention such as a hug, a pat on the back, clapping, saying "Good job," etc. What forms of attention do you think _____ most enjoys?

Response(s) to probe questions:

9. Some children really enjoy certain toys or objects such as puzzles, toy cars, balloons, comic books, flashlight, bubbles, etc. What are _____'s favorite toys or objects?

Response(s) to probe questions:

10. What are some other items or activities that _____ really enjoys?

Response(s) to probe questions:

After completion of the survey, select all the stimuli which could be presented or withdrawn contingent on target behaviors during a session or classroom activity (e.g., a toy could be presented or

Figure 2.2 (*Continued*)

pretreatment baseline. These data are subsequently recorded during each training session to document behavior change as a result of training or other intervention. An example of a task analysis data sheet is shown in figure 2.3.

withdrawn, a walk in the park could not). Write down all of the specific information about each selected stimulus on a 3" x 5" index card (e.g., likes a female adult to read him the "Three Little Pigs" story.) Then have the informant(s) select the 16 stimuli and rank order them using the cards. Finally, list the ranked stimuli below.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____

Notes:

Figure 2.2 (*Continued*)

2.3. APPROACHES TO HELP FAMILY CAREGIVERS AND HEALTH CARE PROVIDERS

The behavior principles, concepts, and procedures described in this chapter have broad generality to assessment, management, and treatment of all types of behavior exhibited by children, adolescents, and adults. All individuals who take care of children and youth whose coping and adjustment

TASK ANALYSIS FOR PHLEBOTOMY

CLIENT: _____

OBSERVER: _____

DATE: _____ TIME: _____

BASELINE: _____ ROLE PLAY: _____ IN VIVO: _____

SESSION: _____

	Step Not Applicable Today	Cooperation	Negative Vocalizations	Escape/ Avoidance
1. Enters examination room.				
2. Sits on chair near exam table.				
3. Allows examination of chest and back with stethoscope.				
4. Allows placement and inflation of blood pressure cuff.				
5. Remains calm while therapist/physician puts on gloves.				
6. Hold hands with the therapist/ physician.				
7. Allows cleansing of site on arm or hand with alcohol swab.				
8. Allows application of cream/topical anesthetic.				
9. Allows placement of rubber tourniquet.				
10. Remains calm while syringe packet is opened (without needle).				
11. Remains calm while syringe packet is opened with needle.				
12. Allows topical pressure on prepared site with gloved finger.				
13. Allows touch with syringe or "butterfly" tubing without needle.				
14. Allows more forceful topical pressure with syringe without needle.				
15. Allows topical pressure with blunt needle or probe.				
16. Allows actual needle insertion.				
17. Remains calm while vials are filled and exchanged.				
18. Remains calm while tourniquet is removed.				
19. Remains calm during needle withdrawal.				
20. Allows application of bandaid on needle site.				

+ = YES **– = NO**

Figure 2.3 Example of a task analysis for defining steps in a medical procedure and for data collection during the procedure. *Source*: Slifer, K.J., Babbitt, R.L., & Cataldo, M.D. (1995). Simulation and counterconditioning as adjuncts to pharmacotherapy for invasive pediatric procedures. *Journal of Developmental and Behavioral Pediatrics*, *16*, 133–141. Reprinted with permission from Lippincott Williams & Wilkins.

are challenged by medical conditions and health care experiences may benefit from learning this information, which comes from the discipline of behavioral psychology or applied behavior analysis (ABA). Many caregivers may be inclined to respond to this material with "I have tried that

and it doesn't work" or "I don't have time for all of that." Caregivers and health care providers are encouraged to review these principles, concepts, and procedures often and to apply them as described here and in subsequent chapters. Many caregivers and providers will be able to independently apply some of this information when caring for children with health conditions. However, if you do not feel that you can do so, it is recommended that you consult a professional behavior analyst, behavior therapist, or pediatric psychologist. The following Web sites are suggested as starting places for help identifying these resources:

http://www.kennedykrieger.org/patient-care/patient-care-programs/outpatient-programs/pediatric-psychology-clinic-and-consultation-service

http://www.abainternational.org/

http://www.apadivisions.org/division-54/index.aspx

2.4. PRINCIPLES, CONCEPTS, AND PROCEDURES

Behavior

Behavior is a concept describing the movement of living organisms. It refers to the portion of an organism's interaction with the environment that is characterized by detectable displacements in space through time of some part of the organism. Behavior must produce a measurable change in some aspect of the environment, and it refers to a set of movements holding in common certain dimensions or functions.[7] In this book when the term *behavior* is used, it will be referring to a directly observable interaction between a person and the physical and social environment or a related, measurable physiological process within that person.

Environment

Although *environment* is a ubiquitous term in contemporary culture, its particular meaning within the context of behavior analysis is important to clarify. Skinner noted that behavior occurs within a frame of reference provided by the organism itself and external objects or fields.[8] Johnston and Pennypacker expanded on this definition to include "the conglomerate of real circumstances in which the organism or a referenced part of it exists."[7] For the purposes of the present discussion, we will describe the environment as the

physical realm in which the pediatric patient exists, including the sights, sounds, other sensations, and particularly the social interactions encountered by the child at the present time or during past learning experiences. Thus, what the child sees, hears, feels, smells, tastes, or otherwise senses in his or her physical setting, along with the social interactions, past and present, experienced by the child, constitute the relevant environmental context in which behavior occurs. Consequently, behavior is strengthened or weakened by temporally associated changes in this context.

Operant Contingency Management Interventions

Most behavioral interventions involve using environmental contingencies or consequences such as positive reinforcement, negative reinforcement, or punishment to change the individual's probability of displaying certain behaviors. Table 2.1 displays a conceptual table that can be helpful in understanding the definitions and relationships among different types of contingencies that are used in behavior analysis and intervention. *Positive reinforcement* occurs when a preferred item or activity is presented "contingent on" (immediately following) a target behavior, and *negative reinforcement* occurs when a nonpreferred item or activity is withdrawn contingent on a target behavior, thereby strengthening its probability of future occurrence. Whether negative or positive, in order to be described as reinforcement, the effect on the target behavior must be to *increase* its frequency or future probability.[9-11]

Extinction is both a behavioral phenomenon and a procedure for reducing the frequency or probability of a target behavior. Extinction involves discontinuing reinforcement of a previously reinforced behavior, resulting in its subsequent reduction or elimination after having been maintained by positive or negative reinforcement.[9-11]

TABLE 2.1 Conceptual Table Showing Relationship between Environmental Stimuli and the Individual's Behavior in Behavior Analysis Contingencies

	Stimulus Presented	Stimulus Withdrawn
Increase Behavior	Positive reinforcement	Negative reinforcement
Decrease Behavior	Type I punishment	Type II punishment

Source: W.H. Morse & R.T. Kelleher (1977). Determinants of reinforcement and punishment (p. 180). In W.K. Honig & J.E.R. Staddon (eds.), *Handbook of Operant Behavior*, 1st ed., © 1977. Reprinted by permission of Pearson Education Inc., Upper Saddle River, NJ.

Punishment is a term that has a specific definition within learning theory and ABA. It refers to any situation in which a behavior is followed by the contingent delivery or withdrawal of a stimulus, and the probability of the behavior occurring in the future is thereby decreased.[9–11] Thus, it is a technique for suppressing unwanted behavior. However, because this technical definition is easily confused with what a layperson might think of as punishment (e.g., physical or corporal punishment, spanking) and because any type of punishment procedure frequently results in unhelpful emotional responding in the learner, punishment is a technique that is rarely recommended with children in medical settings, requires special ethical considerations, and will not be discussed in most of the applications described below. The contingent presentation of an aversive or nonpreferred stimulus (sometimes referred to as type I punishment) is especially likely to produce undesirable and potentially traumatic emotional side effects. This procedure is only used under the rarest circumstances when highly dangerous behavior (self-injury, physical aggression) cannot be modified by less intrusive procedures. Therefore, type I punishment requires review by an institutional ethics committee, should be implemented and monitored by an expert behavior analyst, and is not recommended or discussed further in this book.

On the other hand, type II punishment refers to the contingent withdrawal of a stimulus (item or activity) following a target behavior, which decreases the target behavior's probability of future occurrence. Typically, this involves removal of a reinforcing or preferred item or activity contingent on a target behavior that one aims to reduce in frequency. This type of punishment has been used more often in the form of "time-out from positive reinforcement" or "response cost," both of which involve temporary loss of access to a reinforcing item or activity. Temporary loss of television, computer, or mobile phone privileges is a common example of this type of punishment. Obviously, this type of punishment may still result in frustration, crying, or anger, for example, but usually does not produce more extreme emotional reactions. Nonetheless, even these techniques are rarely necessary and will not be mentioned often in this book.

Differential reinforcement refers to systematically providing preferred items or events (including social attention) in response to those behaviors to be increased in frequency (e.g., compliance, cooperation with care, positive coping responses, participation in therapy, asking for help), but not in response to those one intends to decrease (e.g., aggression, inappropriate language, disturbing medical equipment). This technique is a critical component of every behavioral intervention described in this book. Use of differential

reinforcement by all therapists, parents, and medical caregivers can facilitate a calm, supportive, nonreactive health care environment. It fosters an interaction style in which individuals are encouraged to communicate and interact with professionals and to participate as best they can in medical care and therapies. Staff focuses on acknowledging and rewarding the individual's successes and improvements, no matter how small, rather than emphasizing failure or deficits.

When employing reinforcement strategies, it is important to be aware of the possibility of inadvertently reinforcing problem behavior with social attention. Both positive social attention (asking what is the matter, attempting to soothe) and negative social attention (verbal reprimand) can reinforce problem behavior in some cases. Similarly, if undesirable behavior occurs in response to task demands and the caregiver discontinues the demand in response to the behavior, this may negatively reinforce the problem behavior (the patient is able to escape a nonpreferred demand or situation).

Antecedent Management Intervention

Antecedent management interventions require a systematic assessment of the environmental conditions and internal physiological states that are most frequently associated with problem behavior and those that are associated with positive behavior. These interventions involve proactive modification of the social and physical environment to prevent or minimize the occurrence of undesirable behavior and to increase the probability of appropriate adaptive behavior. Similarly, antecedent intervention may also be directed toward the individual's physiological status by treating pain and other discomforts, such as anxiety or depressive symptoms, sleep disturbance, nausea, uncomfortable room temperature, and ill-fitting orthopedic appliances, that appear to be highly associated with negative behaviors.

The goal of antecedent management is to modify the patient's environment and physiological state (i.e., arousal level) so as to minimize the probability of problem behavior. By identifying and adjusting environmental antecedents of behavior problems, it is possible to make the environment more controlled and safe and less distressing to the patient. Additional examples of these proactive antecedent interventions include (1) decreasing sensory stimulation (e.g., utilizing natural lighting, minimizing the number of people talking at one); (2) decreasing the frequency or duration of medical assessments, treatments, or self-care demands, when possible; (3) avoiding the use of physical management and/or restraints for challeng-

ing behavior; (4) providing distracting preferred activities during uncomfortable treatments, waiting-room time, or other unstructured intervals; (5) providing a predictable routine, including scheduled breaks from uncomfortable treatments; and (6) providing an organizing structure (written daily schedules, rules for behavior, memory journal) for maximum orientation to time, place, and person and for predictability of the environment and daily routine. Finally, during times of anxiety, pain, discomfort, and/or disorientation, medication may be required to reduce acute symptoms.

Antecedent interventions are especially important during periods of diminished consciousness, when contingency learning may be more difficult and inefficient. Furthermore, antecedent management is a crucial intervention when disruptive behavior is severe, dangerous, episodic, and consistently associated with modifiable environmental or physiological variables.

Counterconditioning

Counterconditioning is a technique used to modify anxiety (physiological arousal) that has become conditioned and therefore reliably occurs in the presence of a specific stimulus or environmental situation. This conditioning has resulted from past association between a neutral environmental stimulus and aversive stimulation (e.g., pain, discomfort). For example, children may become anxious, cry, scream, and try to escape when encountering stimuli that they have experienced as painful or uncomfortable. If conditioning has occurred, they also will have a similar behavioral reaction to stimuli that have been physically and temporally associated with the painful stimulus (e.g., medical supplies, an exam table or treatment room, the smell of alcohol or other antiseptics). During counterconditioning, the child's conditioned anxiety is treated by carefully planned, graduated exposure to the feared or nonpreferred stimulus while the child participates in a distracting, relaxing, or otherwise pleasurable activity. The activity must be one that produces an emotional state that is incompatible with anxiety (e.g., pleasure, relaxation). Once the child appears relaxed and to be enjoying the activity, gradual exposure is accomplished by slowly increasing the child's proximity to the feared stimulus and the duration of contact with it.

Shaping

Shaping refers to using differential reinforcement to teach and strengthen successive approximations of a target behavior or sequence of behaviors.

Over time, the behavior exhibited by the individual becomes increasingly similar to the target behavior until the target behavior is mastered and can be directly reinforced.

Escape Prevention

During the procedure referred to as *escape prevention* or *escape extinction*, escape behavior in the presence of a feared or nonpreferred stimulus is blocked or prevented using verbal prompting, redirection to a specific activity or task, and, if necessary, physically blocking escape while gently guiding the child to remain in the situation. By blocking escape behavior, the therapist is able to weaken and eventually extinguish behavior that has been maintained by negative reinforcement.

Single-Subject Experimental Design

The assessment and intervention approaches described in this book have been developed by applied behavior analysts and behavior therapists that have based their work on 50 years of research literature on the experimental analysis of behavior in both laboratory and applied settings. One hallmark of this type of research is the study of one research participant at a time or small groups of participants observed individually as part of the same experiment. In each case, observable target behaviors are operationally defined (location and type of observable motion in relation to the body, others, and the environment, etc.). Once the target behaviors are defined, they are measured using controlled, systematic, and reliable direct observation procedures. These observations are repeated and tracked over time for each individual participant. To the extent possible, the physical and social environment is carefully controlled with the objective of manipulating only one or a few related characteristics of the environment at a time. As these experimental manipulations are conducted, measures of target behaviors are obtained and monitored for changes in, for example, frequency, intensity, and duration. When observable changes are measured, a relationship between environmental change and behavior change is documented. Subsequently, the manipulated variables often may be restored to their original status, and thus the manipulation is "reversed" or "withdrawn." If the manipulation is repeated and the behavior changes again in the same way, then the experimental effect is said to have been "replicated." With each subsequent replication with the same participant or across a

series of individuals, evidence is cumulated to support the existence of a "causal relationship" between the environmental change(s) and a consequent change in the individual's behavior.

2.5. SUPPORTING LITERATURE

This book is based on the psychology of learning and principles of operant (Skinnerian) and respondent (Classical, Pavlovian) conditioning, as well as the scientific conceptualization, theory, and methodology that have come to be known as ABA and the closely related fields of behavioral and cognitive-behavioral psychology. For an in-depth discussion of the history, development, and methods of ABA, the reader is directed to any of a number of recent textbooks about ABA. One relatively recent and comprehensive example is *Applied Behavior Analysis*, 2nd edition, by Cooper, Heron, and Heward.[10] This text provides an excellent introduction to the field of ABA and cites a host of references from other books and journal articles covering the full scope of the field. ABA has its origins in the philosophical and theoretical science of behaviorism beginning with J. B. Watson[12] and B. F. Skinner,[8] as well as the physiological studies of conditioned reflexes beginning with Ivan Pavlov.[13] Cooper, Heron, and Heward[10] provide an excellent outline and discussion of the seminal books, articles, and journals that have been major contributors to the development of behavior analysis as a securely established basic and applied scientific discipline. The reader is directed to the above-mentioned textbook and the many additional sources referenced therein for a detailed presentation and historical perspective on the philosophy and science on which the present book is based.

In the late 1970s a new area of study and practice emerged in the behavioral sciences that began to bridge the divide between medical and behavioral disciplines to study and treat the complex interactions among environmental, behavioral, and physiological variables impacting health. This specialized field was termed *behavioral medicine*,[14-15] and it has relevance to the focus of the present book in that behavior principles and analyses are applied to the problems encountered by medical patients and their caregivers and that are determined by the behavior of the patients, their caregivers, and their health care providers. Behavioral medicine was initially devoted to the health and well-being of adults, and this has remained its predominant focus. However, similar inquiry and practice have focused on the interaction between the behavior and health status of children. As a result, the fields of pediatric behavioral medicine[16-17] and behavioral

pediatrics[17-18] have developed over the past three decades. For a more comprehensive discussion of the scope of research and practice encompassed in these areas, the reader is encouraged to turn to the textbooks cited above. While there are many other fine references in these fields, these particular texts best exemplify the theoretical, conceptual, methodological, and historical roots of the present text.

Pediatric behavioral medicine, behavioral pediatrics, and the material discussed in the chapters that follow are united in a common concern for the health, well-being, and quality of life of pediatric patients, particularly those with special vulnerabilities such as chronic illness and intellectual or developmental disabilities. They also share a research literature and methods aimed at improving knowledge and practice among a diverse, interdisciplinary group of professionals in the behavioral and health sciences.

Numerous books have been written describing the methodological conventions and experimental "rules" to be followed when conducting applied behavior analytic research using single-subject experimental design. However, the general description offered earlier in this chapter captures the essence of the approach employed when conducting single-subject research. A detailed description of techniques for measurement, control of potentially confounding variables, and experimentation using different types of designs with unique strengths and weakness is beyond the scope of this volume. For more detailed background and discussion of the advantages, weaknesses, and challenges involved in each type of single-subject experimental design, the reader is referred to available textbooks on the topic.[19-22]

All of these texts have in common the goal of describing and teaching strategies of inquiry that are characteristic of behavior analysis, which attempts to make sense of the behavior of human beings and animals by studying them one individual at a time and determining changes in behavior that can be observed as physical and social environmental variables are modified systematically.[22]

KEY CONCEPTS

- The concepts discussed in this chapter are based on nearly a century of scientific study within the fields of conditioning, learning, psychology, and behavior analysis.
- Behavior refers to an observable change in or action of a person's body or internal physiology in relation to time and the physical environment.

- An antecedent-behavior-consequence assessment is used to select interventions that modify aspects of a person's social, physical, or internal physiological environment to prevent or minimize the occurrence of unhelpful behavior or increase adaptive coping behavior.
- A reinforcer assessment helps to establish effective consequences for strengthening behavior.
- A task analysis refers to breaking a complex behavior or task into component steps and then presenting them to the learner one step at a time.
- Positive reinforcement occurs when a preferred item or activity is presented following a target behavior.
- Negative reinforcement occurs when a nonpreferred item or activity is withdrawn following a target behavior.
- Both positive and negative reinforcements increase the target behavior.
- Differential reinforcement involves providing preferred items or events in response to behaviors one seeks to increase but not in response to those one intends to decrease.
- Shaping uses differential reinforcement to teach and strengthen successive approximations of a target behavior.
- Extinction involves discontinuing reinforcement of a previously reinforced behavior, resulting in that behavior's subsequent reduction.
- Escape prevention involves blocking or redirecting escape behavior that has been maintained by negative reinforcement.
- During counterconditioning, an individual's distress is reduced by gradual exposure to a feared or nonpreferred stimulus while he or she experiences a pleasurable activity.
- Single-subject experimental designs are used to demonstrate a causal relationship between modification(s) made in the environment and consequent change(s) in behavior.

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Parent-Child Interactions in Medical Situations

IN THIS CHAPTER

- A discussion of adaptive and maladaptive patterns of parent-child interaction that are commonly seen in the context of medical care.
- A review of learning and conditioning that occurs under normal circumstances for a developing child.
- An exploration of how parent-child interactions may be negatively impacted during illness and medical care.
- A discussion of the competing demands on parents of children undergoing medical care and how they can be managed to maintain a healthy, loving parent-child relationship.

3.1. PATIENT POPULATION AND TARGET PROBLEM(S)

The information in this chapter applies primarily to children between 1 and 12 years of age, regardless of diagnosis or developmental level. However, the parent-child interaction patterns that develop during these younger ages can impact both parent and youth behavioral and emotional adjustment across pediatric ages and into adulthood. The problems being addressed are how to recognize the threats to harmonious parent-child interactions that frequently occur in the context of illness and medical care and how to overcome these threats and barriers to maintain a behaviorally and emotionally healthy relationship with the child.

3.2. EXPLANATION AND ILLUSTRATIVE EXAMPLE

What is the most elemental aspect of parenting? Beyond basic reproduction and perpetuation of life lie the instincts to nurture, sustain, and protect one's offspring from harm. Preventing the death, injury, or illness of one's child is the primal motivation of parenting. The corollaries of this motivation are to protect from pain and discomfort (fear, sadness, disappointment). Raising a child is a complicated, emotionally demanding endeavor. Parenting successfully is a challenge as ancient as the first sentient family. When successful, it can be the fulfillment of a lifetime, and if complicated by injury or illness, it can be a source of enormous stress to conscientious parents. This is, no doubt, an oversimplification, but at the most basic level the parent-child relationship involves a developing child whose role is to explore, learn, and grow and a parent whose role is to nurture, protect, and teach.

A hypothetical example will be helpful to begin this discussion. Imagine a 2-year-old child falling and skinning a knee. The child communicates distress through facial expressions of pain and crying. The associated behavior patterns are predictable and can be described in operant behavioral terms. The process involves aversive conditioning on the part of both child and parent (see table 3.1).

The pain-inducing stimulation (tissue irritation or damage) is an aversive stimulus for the child, and behavior that leads to or is regularly associated with the relief of pain is negatively reinforced. Crying and running to the parent are reinforced by the positive attention and comfort provided by the parent (positive reinforcement) and the elimination or reduction of the pain (negative reinforcement) achieved through child-friendly first aid and distraction provided by the parent. From the parent's perspective the cry of the child is an aversive stimulus. Perhaps nothing is as unpleasant and stressful to a parent as the distressed cry of one's child. Consequently, parental behavior that comforts and soothes the child and thereby alleviates the child's crying (terminates an unpleasant stimulus) is negatively reinforced in the parent. Furthermore, assuming adequate capacity for learning and memory, the child and parent will also learn to avoid the situation that led to the aversive stimulation, if at all possible.

So far, this is not too complicated. A stimulus-response-stimulus-response cycle of interaction has been adaptive and effective for both

TABLE 3.1 Negative Reinforcement through Contingent Termination or Removal of an Unpleasant Stimulus during a Parent-Child Interaction

	Unpleasant Stimulus	Behavioral Response	Effect on Future Behavior in Similar Situations
Child's Experience	• Pain from a skinned knee	• Crying	• More likely to cry
		• Distressed facial expression	• More likely to show distressed facial expression
		• Running to parent	• More likely to run to parent • More likely to avoid activity that led to a skinned knee (e.g., running)
Parent's Experience	• Child's crying and other distress behaviors	• Give child affection	• More likely to give affection when child is crying
		• Apply soothing antibiotic cream	• More likely to apply soothing antibiotic cream
		• Saying calming words to the child ("You will be okay.")	• More likely to say calming words when the child is crying
		• Observes child to stop crying and calm down	• More protective behavior to help child avoid injury in similar situations

child and parent. However, even in this simple example, there may be complications. What if the parent is unsuccessful at alleviating the child's pain or performs behavior that, in fact, intensifies the pain (cleans the wounds with soap and water, applies a stinging antiseptic)? Now the parent, normally associated with comfort and alleviation of pain, has become associated with the onset of additional and possibly more intense pain (see table 3.2). A behavior analyst would correctly hypothesize that under similar conditions in the future (another skinned knee) the child is likely to avoid or attempt to escape from his or her mother with an antiseptic bottle in hand. Now, there is conflict between two competing motivations.

For the child, the conflict is between seeking comfort from a parent, who normally is associated with comfort, and avoiding the same parent

TABLE 3.2 Unintended Punishment by Contingent Delivery of an Unpleasant Stimulus during a Parent-Child Interaction

	Unpleasant Stimulus	Behavioral Response	Effect on Future Behavior in Similar Situations
Child's Experience	• Pain from a skinned knee	• Crying • Distressed facial expression • Running to parent	• Tries to suppress crying • Tries not to show distressed facial expressions • More likely to run away and hide from parent • More likely to avoid parent when in pain
Parent's Experience	• Child's crying and other distress behaviors	• Scold child for not being careful • Apply stinging antiseptic medication • Saying, "Stop crying. It can't hurt that much!" • Observes child trying to pull away, block parent's access to wound	• Likely to scold more loudly when child is crying • Less likely to apply same antiseptic medicine (even if prescribed by doctor) • More anxious and less confident about what to do in similar situations in the future

who has recently been associated with pain. For the parent, the conflict is between providing immediate comfort to sooth the child and, if possible, lessen or eliminate aversive stimulation to the child (pain) and the parent (a crying child) and providing painful treatment in order to prevent later aversive consequences (infection, infection-related pain, and more invasive wound treatment). The antiseptic treatment and the associated pain could be avoided and the child's heightened distress prevented. However, this may lead to medical complication. The skinned knee could become infected and result in more pain later when the wound requires more invasive medical care, or in the exceedingly rare and most extreme case, the child could lose the leg or die from sepsis (systemic infection).

If we generalize this discussion to one of thousands of situations encountered by children and their parents or other caregivers every day in medical clinics and hospitals around the world, this scenario is not so far-fetched.

Pediatric patients who experience physical trauma, life-threatening illness, surgery, or invasive diagnostic treatment procedures encounter a host of unpleasant stimuli—associated sights, sounds, and other sensations that have both immediate and delayed effects on behavior, health, and quality of life for the child, parents, siblings, and even extended family. For patients with chronic conditions, painful wounds, infections, and long hospitalizations are common, during which uncomfortable environmental, physiologic, and social stimuli are experienced in countless combinations that produce and maintain complex behavior patterns through conditioning and learning processes.

3.3. SUPPORTING LITERATURE

Several entire intellectual and research disciplines have been devoted to studying and facilitating healthy child development and successful parent-child or caregiver-child interactions (child development, early childhood education, developmental psychology, child clinical psychology, etc.). This chapter does not by any means purport to review these fields comprehensively. Instead, it examines how the developing parent-child relationship has powerful roots in both physical and cultural evolution and is subsequently affected by injury, illness, and medical treatment. Various professional journals such as the *Journal of Pediatric Psychology*, *Children's Healthcare*, and *Health Psychology* are devoted to understanding complex patterns of interactive stimulation and associated behavior and emotions.

3.4. ASSESSMENT PROCEDURES

In the clinic or hospital unit, family and medical caregivers need to make wise and helpful choices when interacting with pediatric patients, but they are not always successful. In addition to the philosophical perspective of behaviorism and cognitive-behavioral principles, this book takes a pragmatic perspective toward parent-child interactions. That is, caregiver behavior either helps to accomplish or impedes important medical objectives (relief of pain, healing, improved physical and social functioning, and better quality of life). Assessment that guides intervention strategies supporting these objectives is desirable and recommended, and those strategies that interfere with these objectives are not recommended and should be discontinued. In general, the assessment techniques involved in antecedent-behavior-consequence (ABC) analyses, reinforcer assessment, and task

analysis of successful coping are the primary assessment strategies and were discussed in chapter 2. Of course, each child, caregiver, and family is unique, and so what is helpful for one may be harmful to another.

Parent-child interaction patterns come in considerable variety and are likely determined by psychosocial history, parent personality, child temperament, and the learning history of both (just to mention a few maintaining variables). Other considerations for both child and parent include level of anxiety, mood (depression, hopelessness), current pain, history of painful experiences, sleep patterns, sleep deprivation, hunger, tendency toward catastrophic thinking, and countless other variables. Parent and child variables interact in a fluid and reciprocal manner that makes ongoing behavioral assessment and problem solving essential to helping them cope successfully with medical care. Therefore, the behavior principles and procedures described in this book have broad generality across pediatric procedures, regimens, and situations but also require individualization for any particular parent-child dyad and situation.

3.5. CONSIDERING THE PERSPECTIVES OF FAMILY CAREGIVERS AND HEALTH CARE PROVIDERS

The remainder of this chapter is devoted to a discussion of common patterns of parent-child interaction which occur in the context of medical care and the behavior principles that seem to apply to the problems and can guide effective solutions in daily practice.

Some parents want, above all else, to be friends with their child and will go to great lengths to avoid upsetting the child. Their belief is that childhood should be a time of safe, blissful innocence and nothing is worse than for the child to be uncomfortable, unhappy, or disappointed. Furthermore, if the child does experience negative emotion, a parent may feel guilty and that he or she has failed the child. This is simply the fear of not being a good parent. For parents who tend toward guilty feelings, uttering the word "no" to their child can be very difficult. Child psychologists encounter such families regularly and have developed parent training programs aimed at teaching parents to recognize that one can place limits on one's child's behavior and still maintain a healthy, positive, loving parent-child relationship.

Parents are particularly vulnerable when their child is ill or has been injured. The natural and appropriate emotion experienced by parents of children with health conditions is empathy for a suffering child. *Suffering*,

however, is a relative term, and some parents see even small discomforts as a source of suffering for their children who have the extra challenges and burdens of health problems with which to contend. The parent often feels sorry for the child and may feel guilt for having caused or not protected the child from illness or injury, and he/she may try to compensate by protecting the child from any discomfort resulting from medical care. Parental behavior that is motivated by guilt and anxiety can become problematic when a child requires repeated and/or invasive medical care. Certainly these are well-meaning and loving parents who, like all of us, only want the best for their children. Parents may resist or refuse necessary pediatric medical care to avoid their child being distressed. In extreme cases, such situations may ultimately require intervention from child protective agencies to ensure that the child receives critical, life, and health-sustaining medical care.

However, this pattern of parent guilt and avoidance of procedures that cause the child discomfort is manifest in myriad lesser ways in pediatric medical settings. Parents and other caregivers may avoid, interrupt, or delay blood tests, injections, medication administration, wound care, and the like to avoid child distress and related behavior problems. This may involve turning away medical staff because the child is sleeping, allowing the child's distress to delay or terminate a medical procedure, and insisting on a specific nurse or physician who is most skillful and efficient at a procedure. They may insist on sedation when it is not warranted. At a certain level these caregiver patterns are good advocacy for the child but, when more extreme, can become disruptive to timely and appropriate care. Highly protective parents are not bad parents; they are motivated to be the best parent they can be, but their tactics may need to be adjusted to be truly helpful to their child's health and development.

3.6. INTERVENTION STRATEGIES

Countering Tendencies toward Overindulgence and Overprotection

In situations where caregivers tend toward overprotection, parent education and training are typically helpful. Parents may need to be taught or reminded that the uncomfortable intervention is necessary to save the child's life or to restore the child to health. Parents may also benefit from education about the competition between immediate and delayed consequences (immediate comfort vs. long-term health benefits and comfort). Direct

parent training can be of great benefit to parents by teaching them specific ways to be of help to their children. This may involve teaching verbal instructions, differential reinforcement, physical guidance, distraction, and coaching techniques. Educating caregivers and modeling for them how their attention and comforting behavior toward the child can be timed differently can be of great help in these situations. For example, trying to sooth and comfort a child during a medical procedure can be disruptive if it delays the needed procedure and teaches the child that behavioral distress delays or prevents an undesired medical procedure. On the other hand, these same behaviors, if timed slightly differently, can decrease the child's focus on discomfort. Parents can effectively assist the child in holding still and participating appropriately in medical care and coach the child in using behavioral coping strategies. Parents can still provide affection and physical comfort that helps a child recover from distress after a procedure has been completed. Most importantly, they can communicate love and affection that strengthens the positive parent-child emotional bond.

Countering a Tendency toward Unhelpful Anger

We have already discussed the factors that may cause a parent or caregiver to be indulgent and protective of a child with health problems. Another pattern is a tendency toward expressing negative emotion such as anger. Life is challenging for all families, but especially for those caring for a child with a chronic, life-threatening disease or life-altering injury. Adults can be angry for many reasons, but one that is likely in a parent with a child having health problems is the random injustice of having an afflicted child. Entire books have been written about the emotional trauma that accompanies one's child experiencing an unexpected injury or receiving a life- or health-threatening diagnosis. The parent may lack the emotional self-regulation skills to cope with the overwhelming distress associated with unpredicted trauma. The result can be an overflow of negative emotion that is expressed to medical staff, health care therapists, other family members, and even the affected child. Out of fear, frustration, and lack of control over life circumstances, these parents may strike out with hurtful accusations and blame others (even the child) for that which is outside of the parents' understanding and/or control. Physicians may be blamed for perceived incompetence, nurses for being inattentive, and spouses for not being helpful enough. The child may be blamed for having contributed to his or her own illness or injury or for lack of cooperation and emotional control.

Angry, aggressive, and demanding behavior may be further exacerbated by mood disorder, food or sleep deprivation, anxiety, and stress related to missing work or managing the care of siblings at home. The hypothesized behavior principle is that of prediction and control of aversive stimulation. Bad or painful things happen to the child and family which the parent cannot predict or control. When aversive stimulation is unavoidable and uncontrollable, a behavior that is common across species is to attack the perceived source of the aversive and uncontrollable situation. In animals, this may involve biting or scratching, but in parents of ill children it usually involves negative verbal behavior. This response pattern can be exacerbated by the child's emotional distress, which ironically may result from witnessing or being the recipient of the parent's displays of negative emotion. Angry, aggressive behavior is typically reinforced because it changes *something* in the environment. Nurses might be frightened away, treatment schedules may be adjusted, and the child may follow directions out of fear. As a result, angry parent behavior is reinforced and resistant to modification.

Angry parents often benefit from interventions that relieve stress caused by such factors as fear of losing one's job, worry about the well-being of siblings, anxiety, or fatigue. Behavioral interventions can be helpful by teaching the parents specific skills for communicating effectively with the medical team, their child, and each other. Most parents can benefit from learning skills for managing their own emotions, organizing the child's unstructured time, and managing their child's behavioral distress. Seeing alternative behaviors modeled, explaining their rationale, coaching their use with the child or health care providers, and providing objective feedback on their performance can help mitigate problematic parenting behaviors.

Countering the Tendency toward Helplessness

Another behavior pattern of parents when interacting with their children in medical settings may be described as "traumatized," "passive," or "helpless." These are caregivers who may be withdrawn, avoid interaction with anyone, cry frequently and easily, or simply sleep at every opportunity. This pattern of behavior is hypothesized as another type of response to repeated unpredictable and uncontrollable aversive stimulation. Such stimulation can include the child's crying and distress, parent's sleep deprivation, a traumatic medical diagnosis, overstimulation from medical staff and

beeping equipment, or too many visitors. The behavioral conceptualization under these circumstances might be compared to Seligman's[1-2] notion of "learned helplessness," which may occur when no response by the parent can eliminate the aversive stimulation, and the parent therefore eventually stops initiating any attempts to cope with or act upon his or her environment.

The recommended behavioral intervention for "learned helplessness" is to alter the environment so that events, especially aversive ones, are more predictable (a structured schedule of medical care, visitation, and activities with the child), as well as arranging for some responses to be reinforced by bringing about preferred change in the environment. This may be accomplished by teaching and prompting pleasurable interactions that the parent can have with the child which will produce desirable changes in the child's behavior. Arranging any opportunity for the child and parent to have appropriate control over some events in their day by giving choices whenever possible and consistently scheduling those over which there is no choice can reinforce social interaction and improved mood in parents who have become traumatized and withdrawn.

Beyond being unresponsive or withdrawn, some parents are simply absent and may appear negligent. Of course, there may be many reasons for a parent to be absent from the hospital or regularly miss their child's medical clinic appointments. Some simply have too many responsibilities and too little social support. These individuals may be working two or even three part-time jobs to support their family and make ends meet. Some are in danger of losing their jobs because of too many absences to be with their child in the hospital or care for an ill child at home. More than anything, these parents need physical, social, and financial support from extended family, social services, and charitable organizations. These parents typically are not absent or uninvolved by choice, but by necessity. They do what they can to stay in touch with medical caregivers and their hospitalized child by phone and to come to essential meetings and appointments.

There may be, however, a few parents/caregivers who are unable emotionally to see their child receiving medical care, in pain, or frightened, or even to be in a medical setting (perhaps he or she had medical trauma as a youth). By working with medical and behavioral staff who are aware of and sympathetic to their experience, these individuals can be helped by a systematic plan of gradual exposure and learning relaxation, distraction, or other emotion regulation strategies. In addition, their visits can be scheduled at times and under circumstances when the child is least likely to be

in pain or undergoing stressful or invasive procedures and is more comfortable. Opportunities to play with the child during these "downtimes" allow the parent to experience the positive reinforcement of pleasant interaction with the child and can be further supported by recognition from behavioral and medical staff for their coping and for helping their child in an important and appropriate way. In this way the child experiences normative and vital social interaction with a parent who is calm, interactive, and positive when visiting, and this can alleviate a child's misinterpretation that he or she did something wrong to upset the parent.

Countering the Tendency to Intellectualize

Still other parents or caregivers avoid the aversive experience of witnessing the child's distress and their own helplessness to alleviate it in a mental (cognitive) rather than physical way. These are individuals who respond to stress by a process of what some might term "intellectualization." These individuals may seek every bit of information they can get about their child's condition and treatment by asking questions, reading books and articles, searching the Internet, or seeking other opinions. In proper perspective these behaviors are good advocacy. Intelligent and well-informed caregivers understand that they have a role and a voice on the treatment team, and that their eyes, ears, hands, and talents can assist in the child's care and monitoring. On the other hand, those who become too engrossed in their quest to understand and direct the child's treatment may be avoiding thinking about or experiencing their child's discomfort and their own negative emotions about their child's discomfort. The behavior of these individuals may be reinforced by the avoidance of negative thoughts and emotions about the child's diagnosis, prognosis, and suffering; by the control they exert over the environment (affecting change in staff, routines, daily care); and by the social interaction with medical professionals. The recommended behavioral intervention for "intellectualizing" is to prompt and provide differential reinforcement for helpful behavior by including parents at appropriate times in treatment team discussions and involving them in the daily care of the child by letting them perform activities of daily living (bathing, feeding, assisting with positioning, and the like). Giving them a voice in choosing among equally acceptable options for care and providing scheduled and time-limited opportunities to meet with attending physicians, nurse managers, and psychologists can reinforce appropriate involvement, allow reasonable and safe control over the environment,

and meet parents' needs for information and discussion of their child's condition.

In addition, an "intellectualizing" parent may benefit from education about and reinforcement of their vital role in providing social support, physical comfort, entertainment, love, and affection to their child. Prompting and reinforcing these attachment-based parenting behaviors reminds the parents that their nurturing behavior is as important to their child's healing, recovery, psychological well-being, and quality of life as the technical aspects of medical treatment and nursing care. As always, warm, balanced, positive parent interactions with their child can strengthen the child's ability to cope, relax, and even enjoy positive aspects of the medical environment. Seeing their child relaxed, comfortable, and engaged in pleasant activities can strengthen the parents' positive coping and reinforce their appropriate caregiving behavior. Seeing their parents relaxed and behaving as usual can in turn comfort and relax the child. In this way, the intellectual parent can be shown the value of their parenting behaviors while giving them important control over aspects of the medical environment, counterconditioning their emotional arousal in the medical context, and thereby decreasing their anxiety about their child's condition and the status of their family.

Countering the Tendency to Be Authoritarian

Another parent-child interaction pattern sometimes observed when children are undergoing medical care might be characterized as "misguided." This involves a parent who has strong opinions about how children should be raised, what behavior is expected, and what behavior will not be tolerated. This style of parenting has been referred to by some as "authoritarian." Perhaps the most likely behavioral hypothesis about the motivation of this behavior is that the child's "misbehavior" or distress is distressing or otherwise aversive to the caregiver. This may be because the child's behavior is not congruent with the caregiver's beliefs and attitudes about how children should behave. It also might make the parent feel embarrassed, helpless, or afraid of social judgment of his or her ability to be a successful parent. Thus, scolding, criticism, or threats of punishment may be used to attempt to suppress any behavior of which the caregiver disapproves. Harsh, critical, and demanding caregiver behaviors may be negatively reinforced by immediately suppressing the child's undesirable behavior even if the suppression is only temporary.

However, with the stress, confusion, anxiety, and discomfort experienced by a child during repeated invasive medical routines, the child may not be able to maintain the attention span and emotional/behavioral self-control required to meet the caregiver's demands. When the child loses control, cries, or attempts to avoid or escape the medical care, the caregiver will redouble efforts to control the child's behavior. In this way an escalating pattern of increasing frequency, volume, and negativity can ensue, followed by increasing distress and avoidance behavior on the part of the child. Sometimes this pattern can escalate to aggression or elopement by the child and, in extreme cases, abusive behavior from the caregiver, requiring intervention from others to protect both child and parent. Clearly this is an unfortunate state of affairs that began with a well-intended caregiver and a child who was likely eager to please. Yet a predictable and avoidable pattern of negative interaction has evolved. This misguided approach to managing child behavior can be further exacerbated by sleep deprivation, fatigue, chronic pain, anxiety, depression, or mental illness of the caregiver. Each of these variables can make an already-aversive situation even worse.

Behavioral intervention under these circumstances requires an interruption of this interactive pattern of behavior. Environmental or medical intervention is needed to mitigate aggravating variables (depression, sleep deprivation, anxiety) and to teach the caregiver alternative and more effective skills for managing child behavior. The chapter that follows will elaborate on behavioral parent training to teach effective behavior management skills. Suffice it here to say that education, modeling, rehearsal, and differential feedback on helpful versus nonrecommended caregiver behaviors are required and can be effective in facilitating more positive and mutually reinforcing caregiver-child interactions.

No claim is made here that the above discussion is comprehensive and covers all possible styles of parent-child interactions. It does hopefully make clear the multitude of variables that influence these interactions, the complexity of assessing them, and the need for effective, individualized behavioral interventions that are based on a functional assessment of maintaining environmental, biological, and psychosocial variables.

Encouraging Healthy Adjustment to Illness, Injury, and Medical Care

To conclude this discussion of parent-child interaction patterns in families receiving pediatric medical care, we will consider characteristics of parents

or caregivers that may best enable them to cope with the extra stress and demands on time, energy, and resources caused by pediatric health problems and related care. One ideal is to help caregivers be self-aware in the sense that they know some behavior principles and are able to perceive how their behavioral and emotional responses affect those of the child. Self-aware individuals recognize that behavior is motivated by many overlapping and interacting variables. Therefore, she or he is able and willing to observe her or his own behavior and that of the child and health care providers and to assess the associations among them in this constantly changing system. The self-aware caregiver is able to learn from these observed associations, make adjustments in his or her own behavior, and observe the effects of the change. Changes that are associated with improvements in child behavior are retained, and those associated with more problematic child behavior are discontinued.

One last ideal is offered here, which is the notion of a spiritual caregiver. Whether referring to religious or humanistic beliefs, the spiritual caregiver is able to be motivated by thoughts or cognitions that allow for adjustment to existing, apparently uncontrollable circumstances by modifying their own thoughts. For example, instead of thinking "My child is sick and in pain and might die," a more positive and hopeful thought pattern can be adopted and rehearsed, such as "My child has health problems that require medical care and extra love and support. Even though he is not doing well and is in pain right now, with appropriate care from his medical team and me, he may feel better tomorrow, and enjoy the best possible quality of life we can assist him in maintaining." This attitude and associated parenting behavior are motivated by the ability to modify one's thinking toward optimism, hope, or faith. While behavior therapists cannot and should not tell parents what they must think, feel, and do, they can attempt to teach parents that their thoughts, emotions, and behavior have observable and often predictable influences on their child's thoughts, behaviors, and emotions. Parents who are thus empowered are open to changing their own behavior and maintain hope that their own efforts and those of the medical team can sustain their child and his or her quality of life for as long as possible.

KEY CONCEPTS

- Children with medical conditions experience uncomfortable environmental, physiological, and social stimulation that can

produce and maintain complex behavior patterns through conditioning and learning processes.

- Caregivers who are coping effectively are aware of how their own behavioral and emotional responses affect those of the children under their care.
- Some parents and other caregivers may need help recognizing that child behavior and adjustment are motivated by many interacting variables, including parent or caregiver behavior.
- The self-aware caregiver learns from observed associations between his or her child's behavior and his or her own behavior and then makes adjustments in his or her own behavior and observes the effects on the child's behavior.
- Adjustments in parent behavior that are associated with improvements in child behavior should be retained, and those associated with undesirable child behavior should be discontinued.
- Cognitive-behavioral therapists can help parents recognize that their thoughts, emotions, and behavior have observable and predictable influences on their child's thoughts, behaviors, and emotions.
- Well-adjusted, optimistic parents and caregivers are open to changing their own thoughts to maintain hope that their own efforts and those of the medical team can sustain their child's health and quality of life for as long as possible.

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Fundamentals of General Behavior Management for Parents and Other Caregivers

IN THIS CHAPTER

- General parent training suggestions for families and health care providers.
- Information to help parents and caregivers of children with health problems understand child behavior (both positive and negative) that occurs during medical care.
- Strategies for observing, analyzing, and modifying behavior problems.
- Ideas for teaching children cooperative and healthy behaviors for coping with medical problems and their treatment.

4.1. PATIENT POPULATION AND TARGET PROBLEM(S)

The information in this chapter applies to all children and youth, but especially to those who are displaying challenging behaviors that occur during medical care for illness, injury, and related rehabilitation. As introduced in chapter 3, one of the roles required of parents, especially with younger children, is to manage their child's behavior under stressful circumstances. For many parents and caregivers, managing a child's behavior is a daunting challenge under normal circumstances. This can become a major problem under the extraordinary circumstances of chronic, sometimes life-threatening illness or long-term disability. All of the interventions described in subsequent chapters depend for success on the ability of caregivers to obtain cooperation from their children. General parent training suggestions that are relevant to

all situations and that can be used by families and health care providers to gain the cooperation of children and youth are presented in this chapter.

4.2. ASSESSMENT PROCEDURES

Sometimes children, like all of us, behave in ways that seem irrational. In the case of children with medical conditions, their behavior may even be self-destructive (refusal to take medicine, pulling out feeding tubes, food refusal). However, even when it is not obvious, behavior typically is motivated by the effects it has on the physical and social environment. Simply put, behavior occurs for a reason. Sometimes the reason is clear, conscious, and premeditated, but often individuals lack insight into and are not able to explain why they behave as they do. Yet in our daily lives we are all behavior analysts involved in modifying our own behavior and that of others in our world. As people, as parents, as health care providers, and as behavior analysts, we study, question, and influence the motivation of others. We observe our children's behavior, and based on our observations, we construct explanations for why the behavior occurs (he is crying because he is hungry, she is running because she is afraid, etc.).

In general, behavior analysts hypothesize that the occurrence of behavior is due to three types of determinants: environmental situations (antecedents), internal biological states, and social and environmental consequences. The nearly infinite combinations of these determinants in the present moment and during past experience determine the vast complexity and variety of human behavior.

Parents and caregivers of children with medical conditions can learn to assess the reasons child behaviors occur as they do in anticipation of, during, and after medical care. Armed with skills for observing and analyzing behavior and well-established techniques for modifying behavior, caregivers can anticipate, prevent, or at least manage behavior problems, while also teaching and strengthening cooperative and healthy behavior.

4.3. APPROACHES TO HELP FAMILY CAREGIVERS AND HEALTH CARE PROVIDERS

Many parents and caregivers have high expectations of children and adolescents. They often believe that children should behave well, because they should be self-motivated to do "the right thing," and that they are somehow born with an innate sense of right and wrong. If their children

are lacking in this innate moral sense, they should, at the very least, behave well because they are told what to do. Parents and caregivers with such expectations are often destined to be disappointed in and frustrated with their children's behavior. Behavior analysts believe that child behavior is constantly influenced by its consequences, and parents and others who interact with children teach them by example (this is called modeling or observational learning) and by the consequences they provide. For example, in infancy the child may experience the discomfort of hunger, and when she cries, her mother feeds her. So in this basic example, crying is strengthened ("reinforced") because of its consequences—food is provided and hunger is eliminated. In this example both positive (the taste, texture, and warmth of milk in the mouth) and negative (reduction of hunger) reinforcements are occurring.

It is easy to see that as parents meet the child's basic needs for food and comfort, they teach their child to behave in certain ways. In time, parent attention can become a "conditioned reinforcer" because of its repeated pairing with primary reinforcers such as food, drink, comforting, and removal of uncomfortable stimulation. Most behavioral parent training manuals begin with the observation and assertion that parent (or other caregiver) attention is positively reinforcing and children will go to great lengths to get it. Indeed, in clinical practice it is regularly observed that child behavior can be reinforced by positive attention (praise, smiles, physical affection) and in many situations by negative attention (scolding, shouting, and threatening). On the other hand, there are situations in which parent behaviors can function as punishers, thereby decreasing the future occurrence of the child behavior that they follow. Consider, for example, the likely effect of kissing one's teenage son in the presence of his peers. What may be intended as a positive gesture or consequence by a parent can in reality have quite the opposite effect on child behavior. The teenage boy in this scenario will begin to avoid his mother when his friends are around.

So it is that, whether we admit it or not, our attention or lack thereof to our children has a powerful effect on their behavior. Given this observation, it follows that parents and caregivers can give or withhold their attention strategically to modify child behavior. By doing so consciously and with awareness of the power of their influence on their children's behavior, caregivers can provide their attention systematically to strengthen desirable behavior and not strengthen undesirable behavior. Assuming that parental or caregiver attention is an effective reinforcer or motivator, then

giving and withholding attention is an example of "differential positive reinforcement," which is discussed in more detail below.

"Bribes," Rewards, and Reinforcers

Many parents are quick to say either "I don't believe in bribing my child" or "I tried bribing my child, but it didn't work." Webster's dictionary defines a bribe as follows: "a price, reward, gift or favor bestowed or promised with a view to corrupt judgment or conduct." The implication is that a bribe is given or promised in order to get someone to engage in a wrong or immoral act. While it is true that a bribe may increase the frequency of a target behavior, thereby meeting the technical definition of a reinforcer, it is not true that all reinforcers are bribes. On the contrary, if a reinforcer is used to increase the probability of appropriate conduct, it does not meet the definition of a bribe. A positive reinforcer, when used consciously, strengthens positive, socially acceptable behavior, rather than the opposite (negative, inappropriate or immoral behavior). It is therefore more fitting to think of reinforcement as analogous to a reward, defined by Webster's as "that which is given in return for achievement or service."

Throughout this book when discussing positive reinforcement for a child's good or appropriate behavior, we are referring to something given in return for a positive behavior and intended to make that and similarly positive child behaviors more likely to occur in the future. The intention is to motivate rather than to coerce. To any parent or caregiver who objects to reinforcing a child's positive behavior with a material or tangible item, I would ask if they would give up their future paychecks and refuse to accept money or material of any kind for their own hard day's work. Parents might be encouraged to consider that the "work" of childhood is growing, developing, and learning to behave in socially appropriate ways in order to become well-adjusted productive members of society. Providing positive events contingent on a child's "good work" of this kind would seem to be a truly moral act on the part of a parent or caregiver.

Things versus Activities within a Supportive Relationship

Caregivers may mistakenly think that the only reinforcers that will motivate a child are material things, such as toys, snacks, or computer games. While these things may indeed function as effective reinforcers, they are by no means the most important. By and large, children tend to be motivated

by time with, attention from, and interaction with important caregivers or role models in their lives. Therefore, social activities are often some of the most effective motivators for children. Watching and praising a child's play, playing a game of "tag" or a board game together, going to a local playground, and watching a TV show together are but a few examples of activities that can be powerful reinforcers for children and cost caregivers nothing but a little time. For children in the hospital a caregiver's time and attention can be a very effective source of motivation. As we will see in subsequent chapters, activity-based reinforcers, if provided contingent on the right behaviors, can support a child's cooperation and positive coping in the face of challenging, uncomfortable, and even painful conditions.

Presenting Effective Caregiver Instructions

Every basic behavioral parent training manual begins with a discussion of the importance of appropriate verbal instructions in child rearing. Parents often overestimate their child's ability to comprehend and follow complex instructions. As a general rule, using the fewest and simplest words to instruct a child increases the chances that the instruction will be followed. Tasks that require a series of behaviors may need to be reduced to individual steps. For example, instead of telling a child to go put their toys away, wash their hands, change their shirt, and come to dinner, each of these steps may need to be prompted one at a time or, for older children who can read, written down. Such strategies eliminate problems associated with receptive language, memory, and attention deficits. They also provide the opportunity for positive reinforcement of compliance and corrective feedback for performance errors. A related recommendation is to limit the amount of repetition of the same instruction. Caregivers who are stressed and impatient have a tendency to rapidly repeat an instruction without giving their child time to comprehend and act on the instruction. Children often are judged to be "noncompliant" when they don't understand the caregiver's verbal instruction or have not been given time to translate words into action.

An additional characteristic of effective caregiver instructions is that they require follow-through. If an instruction is given to a child, but the child is not required to follow it, then whatever behavior the child exhibited instead may be negatively reinforced by avoidance of a task that is nonpreferred and perhaps unpleasant from the child's perspective. If I tell my child to come here and instead he runs in the other direction and I

allow him to do so, then going in the other direction will probably be negatively reinforced. If I prevent his running away or catch him and guide him to the intended location, I will have implemented an "escape extinction" procedure and will have the opportunity to positively reinforce an approximation of a positive behavior (coming to me when told to do so, even though requiring guidance from his father).

Teaching Child Skills versus Eliminating Problem Behaviors

The behavioral principles and strategies discussed thus far in this book can be used for two purposes: decreasing problem behavior and teaching new behavioral skills. While both are necessary in child rearing and in managing child behavior in medical situations, there is a tendency for caregivers and referring health care professionals to focus on eliminating problem behavior. Behavior analysts believe that it is easier to teach a child what to do than to teach what *not* to do. This book focuses on strategies that emphasize teaching children, adolescents, and caregivers skills that allow them to successfully and more comfortably cooperate with challenging health care situations. The principles and procedures discussed in this book can be used to teach skills for coping with discomfort, following instructions, participating in medical self-care, and adherence with prescribed medical procedures or self-care instructions. They have been used in clinical practice to teach children what to do during medical procedures rather than merely punishing behavior that is disruptive to the procedures.

4.4. INTERVENTION PROCEDURES

Catch Them Being Good

This is likely the most common of all behavior management strategies recommended to parents, teachers, and caregivers. It is an elegantly simple concept but is foreign to so many. We all have the tendency to "let sleeping dogs lie," or to avoid "rocking the boat." For example, if a child is quietly playing and causing no trouble, we tend to leave him alone for fear of "breaking the spell." If we were to speak to or otherwise interact with him, he may begin to misbehave. To the contrary, behavioral psychologists have demonstrated countless times that just the opposite is needed to teach a child to behave well. The primary objective of nearly every behavior management plan for children is for the caregiver to observe the child for

examples of positive, desirable behavior and to give positive attention "contingent on" (during or immediately after) that behavior. Positive attention can be in many forms: praise, a smile, a hug, or a hand shake. Important ingredients include eye contact, positive tone of voice and facial expressions, and words or gestures that communicate pleasure or approval. Depending on their physical state (e.g., fatigue, hunger, anxiety) and temperament, children vary in terms of the type of attention they prefer. Some respond better to a quiet hug, others to loud enthusiastic praise. However, as a general rule of thumb, one can scarcely give quiet positive praise too frequently. As long as it is given in response to appropriate child behavior, the more often, the better!

Planned Ignoring

An equally powerful behavior management tool is based on the behavior principle of "extinction," which involves withholding or eliminating reinforcement when an undesirable behavior occurs. Planned ignoring is the opposite of "catch them being good." Planned ignoring involves deliberate, strategic withholding of caregiver attention when problem behavior is occurring. For example, when a child is having a temper tantrum, the caregiver does not respond to it (does not scold, look at, speak to, speak about, or otherwise notice the child or behavior in any way). The obvious disclaimer for planned ignoring is that it is not to be used for behavior that threatens the child's or anyone else's safety.

It Will Get Worse Before It Gets Better

Any caregiver who decides to use planned ignoring should be forewarned about the likely initial response of the child to withdrawal or withholding of previously provided reinforcement. In the case of a child whose tantrums have been reinforced with adult attention, when the caregiver no longer attends to the tantrum, the behavior is likely to escalate to a higher intensity or other form. For example, when lying on the floor kicking and screaming no longer results in adult attention, the child may begin to cough, gag, and retch or attempt to break a nearby chair. Under these circumstances, any dangerous item should be removed without comment, the child's safety monitored, but the planned ignoring continued. Another way to think of this behavioral escalation (referred to by behavior analysts as an "extinction burst") is that the child is testing the caregiver's limits. That is, he or

she is testing if the caregiver will "give in" and provide the reinforcement after all (in this example, this would mean relenting and giving attention to the child and his or her disruptive behavior). Giving in at this point only further strengthens the problem behavior. In fact, it reinforces the more intensely disruptive behavior. Therefore, another "standard" of behavior modification is that if one begins to use extinction (planned ignoring) for a problem behavior, it must be ignored until the child discontinues it (e.g., calms down from the tantrum). The caregiver must "see it through." Otherwise, it would be wiser to give attention to the milder tantrum just as soon as it begins. Nonetheless, for the caregiver who continues to ignore and "waits out" the tantrum, the longer-term benefit will be a decrease in the likelihood that a tantrum will occur again in the future.

Many a parent has stumbled and given in to child misbehavior, not understanding that planned ignoring (like all behavior modification techniques) involves a process of teaching a child how to behave and will not be instantaneously effective. The parent who is able to keep in mind that he or she is a teacher involved in an ongoing process of socializing a child is better able to persist with a strategy that in the current moment does not appear to be effective. Children learn over time and with repetition of consistent consequences for the same behavior. Accordingly, these behaviors change gradually over time. For this reason parents are encouraged to take "the long view of behavior change." This requires an act of faith that behavioral scientists have documented a set of behavior principles that work reliably with many different individuals and situations. While behavior is never so simple as to be reduced to an unchanging formula, well-established behavior principles can guide us as caregivers with a general road map that will direct us toward more successful and positive interactions with our children. This is just as true in medical settings with chronically ill children as it is in the home or classroom with a healthy, typically developing child.

Differential Reinforcement and Differential Attention

Differential reinforcement involves the strategic combination of reinforcement and extinction procedures. In short, reinforcement is delivered contingent on (during or after) the behavior that one wishes to strengthen and withheld (extinction) when behavior occurs that one wishes to weaken. The most common example of differential reinforcement used in behavioral parent training is differential social attention. This is based on

the observation that child behavior is motivated by the response it produces from parents or caregivers. In this example, differential reinforcement takes the form of "catching them being good" and planned ignoring for undesirable behavior.

Time Out from Positive Reinforcement

It is likely that every parent has heard of "time-out." Most commonly parents instruct their child to "take a time-out" to "calm down" when the child's behavior is too active or disruptive. In some cases, if the child follows instructions, this can prevent escalating problem behavior. What is less well understood is that time-out is most reliably effective when it involves time out "from reinforcement." In the typical situation this means time-out from positive reinforcement in the form of temporary loss of caregiver attention and access to favorite activities. For this strategy to be effective, the reinforcer must be withheld by the caregiver (ignoring, turning one's back, going to a different room), or the child must be removed from the opportunity to obtain reinforcement (chair or corner time-out away from toys and favorite activities). If the problem behavior is being maintained by the reinforcement it produces, then contingent time-out from positive reinforcement will result over time in a decrease in the strength and frequency of the problem behavior.

Other Types of Reinforcement

Behavior analysts are fond of saying that reinforcers are idiosyncratic (unique to the individual). Nearly every event, activity, or stimulus has the potential to be reinforcing depending on the individual and situation. For example, receiving a chocolate ice cream cone may be a reinforcer for me, if I prefer the taste of chocolate and I have not had ice cream recently. If I just ate chocolate ice cream five minutes ago, an additional serving may not be as reinforcing. If I just attended a birthday party and was overstuffed with ice cream and cake, more ice cream may not be a reinforcer at all. Similarly, if I do not prefer the taste of chocolate, then chocolate ice cream may never function as a reinforcer for my behavior.

We all have stimulus preferences and varying degrees of interest in or appetite for a given stimulus at any particular point in time. Therefore, behavior analysts and caregivers who wish to effectively employ behavioral

techniques must be aware of a child's stimulus preferences and the child's relative appetite for access to preferred stimuli.

Reinforcer or Stimulus Preference Assessment

This topic, along with associated assessment strategies, was introduced in chapter 2, but because of its importance to effective planning and implementation of behavior management interventions of all kinds, review here seems warranted. There are several ways to assess preferences and select reinforcers for a behavior management plan. The simplest approach is to ask the child and/or parent what items or activities the child likes. This is the least reliable approach because verbal behavior does not always correspond with physical behavior and because of changing states of interest in or appetite for a given stimulus (item or activity). I might tell you today that I like fishing, but if I see you next Thursday and fished all day on Wednesday, I may have little motivation to go fishing with you. Another approach to reinforcer selection involves conducting direct observation of what the individual does and how she spends her time. If a child plays with the same toy or watches a certain type of video every day after school, these activities may be effective positive reinforcers for doing homework, if the child is only allowed to have access to them after completing homework. If this contingency is reliably arranged and enforced, then completing homework after school should increase. If it does increase, then we can say that contingent access to the activity is a positive reinforcer for that child (but not necessarily for *all* children). The use of a frequently occurring behavior (playing with a preferred toy) to reinforce an infrequent behavior (doing homework after school) has been termed the Premack principle, named after David Premack, who first introduced this strategy in 1959.[1]

The most reliable way of identifying a reinforcer is to make an item or activity contingent on a selected behavior and observe if the behavior increases in frequency as a result. However, this approach alone would be inefficient and impractical. It would be akin to trial-and-error assessment. A more efficient and commonly employed technique is to conduct a systematic stimulus preference assessment. First, a pool of potentially reinforcing stimuli is established based on an interview, questionnaire, or direct observation. Next, each item in the pool is sequentially paired with every other item to offer the individual a series of choices. The individual expresses his or her preference by selecting or interacting with one of the

choices in each pair. Preference can be ascertained by pointing to, touching, selecting, or interacting with one of the items, or by measuring and comparing the duration of time the individual interacts with each item. The item selected most often or interacted with for the greatest duration of time is the one that is preferred. In a sequence of trials each item is compared with every other item for a standard number of repetitions. Then the frequency of being selected or the amount of time the person interacted with each item is calculated and compared across items, and with this information, the potential reinforcers are organized from most to least preferred. The most probable item or the one that is interacted with for the greatest duration is regarded to be the most likely to function as a reinforcer if consistently presented contingent on a target behavior.[2]

Deprivation versus Satiation

These two terms represent the opposite ends of a motivational continuum. The effectiveness of a reinforcer is determined by the extent that the individual is at a state of deprivation for it. To use the ice cream example discussed above, if I have not had ice cream for many days, I am at a greater deprivation for it and am likely to expend greater effort to obtain it. If I work every day at an ice cream shop and eat as much as I like every day, then ice cream is unlikely to be an effective reinforcer for me. I am likely "satiated" with respect to ice cream and will expend little if any effort to obtain more. Thus, in selecting reinforcers to motivate change in a child's behavior, it is necessary to select reinforcers carefully and to arrange the environment to limit the child's access to the chosen reinforcers. For example, the opportunity to watch a movie may not be a very effective reinforcer if the child has been watching movies all day long. On the other hand, if the child has not watched a movie in several days, then earning access to a new movie that he or she has never seen before may be quite effective in increasing a targeted cooperative behavior.

Conditioned or Secondary Reinforcers

Primary reinforcers are thought of as those that have some basic biological function for the individual. Food, drink, comfortable temperature, physical safety, and comfort of any kind are examples of reinforcers that have their effect as a result of allowing the person to maintain a consistent biological state. Other stimuli or events can acquire reinforcing value by vir-

tue of being associated by time and location with a primary reinforcer. Praise, physical affection, eye contact, or social attention of any type may function as a reinforcer because it has been paired with primary reinforcement during development. We each have a unique "learning history" that has been acquired over time through this process of association and conditioning. The process by which various stimuli and activities in our environment acquire reinforcing value by pairing with already-established reinforcers has been termed *second-order* or *tertiary conditioning*. Understanding this process is important when developing reinforcement systems to employ in behavior management or modification.

4.5. EXAMPLES TO ILLUSTRATE IMPORTANT CONCEPTS AND TECHNIQUES

Some reinforcers cannot be provided continuously. Therefore, reinforcement may need to be scheduled after a certain time period (an interval schedule), after a certain number of responses (a ratio schedule), or some combination of the two (concurrent or complex schedules). Why is this important for children in medical settings? An example will help to answer this question. Suppose that the reinforcer maintaining a child's coping behavior during a medical procedure is the opportunity to ride a bicycle. Riding a bicycle continuously during a bandage change would be so disruptive as to be absurd. On the other hand, providing the child with a tangible representation of that activity may serve as a "conditioned reinforcer." If the child is awarded a star on a chart for each minute of cooperation during the dressing change, these stars can be exchanged for minutes of opportunity to ride a bicycle in the hallway later after the dressing change has been completed. The stars acquire value by virtue of being associated with access to the bicycle.

Stimuli such as stars, stickers, tokens, coins, and numerical "points" that have been associated with many different "backup" reinforcers have been described by behavior analysts as "generalized conditioned reinforcers." The best and most familiar example of a generalized conditioned reinforcer in everyday use around the world is money. Money can be used to obtain a virtually endless variety of activities, material goods, and services. While some may object to using money to reinforce good behavior in a child, they would likely object less to using "Monopoly money" or "kiddie bucks" to reinforce appropriate child behavior via subsequent exchange for access to preferred treats or activities. As will be mentioned in subsequent chapters,

these types of "tokens" can be used in a variety of medical situations to motivate cooperation and coping in children with medical conditions. The systematic use of tokens in this way to motivate appropriate behavior may be described as a "token economy" in which tokens or other forms of generalized conditioned reinforcers are exchanged for a variety of tangible items or social activities.

Aversive Conditioning and Negative Reinforcement in Child Behavior and Behavior Management Techniques

The conceptual basis of aversive conditioning was discussed previously, but the nature of negative reinforcement merits review here. Negative reinforcement occurs when an aversive (nonpreferred, uncomfortable, unpleasant) stimulus is terminated by the occurrence of a behavioral response and that behavior is subsequently strengthened (occurs more frequently). For example, if a child has an itchy rash and scratching it alleviates the itch (even temporarily) and scratching increases in frequency, then scratching has been negatively reinforced. While we would never choose to provide aversive stimulation to a child in order to use its removal as a negative reinforcer, it is important to recognize that in many situations a child's behavior may be motivated by an escape or avoidance function. Consider a child who turns away when a nonpreferred food is presented. If turning away allows the child to escape the taste or texture of a nonpreferred food and this behavior occurs more frequently as a result, then we may say that the head-turning behavior has been negatively reinforced and is "escape motivated." When designing behavior management programs, it may be necessary to prevent negative reinforcement of problem behavior by carefully controlling the child's learning environment.

Escape-motivated problem behavior is gradually extinguished by preventing escape in a technique that has been termed *escape extinction*. Another example may be helpful here. If a child dislikes the sensation of having his face washed (aversive stimulation from the child's perspective), then he may cry, turn away, or push away the wet cloth when his mother attempts to wash his face. If his mother gives in and allows the child to escape face washing, the child's avoidant behavior will be negatively reinforced and more likely to occur when face washing is again attempted. As an antecedent intervention, one might use a softer cloth or less pressure for washing the child's face. This may mitigate the unpleasant stimulation for the child and thereby prevent escape-motivated problem behavior. How-

ever, when it is not possible to completely eliminate uncomfortable stimulation involved in a necessary child care activity, three additional strategies may be helpful. Escape extinction would involve persisting with the face washing while blocking the child's attempts to avoid it. With repetition the avoidance behavior would be expected to decrease in frequency and eventually cease. The child learns that the sensation is unavoidable. Escape or avoidance behavior that is no longer reinforced will eventually be extinguished. A second strategy that may decrease escape/avoidance-motivated behavior is a signal provided to help the child predict the onset and termination of the aversive stimulus. In the face-washing example such a signal could be provided if the caregiver were to always count to five or sing the same phrase of a song during face washing. Thus, aversive stimulation that is predictable in onset and duration may be experienced as less unpleasant.

The hypothesized role of aversive conditioning and escape-motivated disruptive behavior will be discussed further in the context of the intervention protocols presented in subsequent chapters. For the present discussion, one additional intervention strategy is "scheduled breaks," which can be helpful in managing escape-motivated child behavior. Consider the problem of a child requiring repeated wound care (cleaning and removal of dead tissue). Such a procedure can be painful, but not always painful, protracted, or frequent enough to justify sedation or anesthesia. In addition to learning and practicing pain-coping strategies such as distraction, deep breathing, or visual imagery (techniques discussed in later chapters of this book), a child might also be provided with the means of predicting and at least partially controlling the aversive stimulation. This has been accomplished in clinical practice by using a timer that signals the beginning and end of an interval of the aversive procedure in combination with providing the child with a limited number of break cards. If the child presents a break card, the procedure can be temporarily terminated (e.g., 20-second break) but not completely avoided. In clinical practice children who have been provided such simple means of prediction and control of aversive stimulation have exhibited striking reductions in escape-motivated distress and disruptive behavior. They also have shown surprising forethought and planning in their use of the allotted break cards.

4.6. CONSIDERATION FOR SPECIAL POPULATIONS

With relatively simple but powerful techniques and systematic training, even very young children and those with intellectual and developmental

disabilities can learn to cooperate with and participate in their own medical care to a degree that seems magical to those who don't witness the training. In fact, they can learn to participate at a level that equals and sometimes surpasses the coping of adults in similarly challenging situations. It is this remarkable (typically unrecognized) capacity and resilience of children, especially those with disabilities and/or chronic health conditions, that has motivated writing this book. It is of critical importance to remember that we all require time and practice to learn more skills. Generally speaking, the more difficult the skill to be mastered, the more time and practice are needed. An additional rule of thumb is, the younger the child or the greater his or her intellectual or developmental disability, the more time and practice will be required to master a new skill. Oftentimes, a slower rate of learning is inappropriately interpreted by caregivers as the child's inability to learn. For this reason children may not be given the preparation and opportunity to gain new skills needed to cooperate with and benefit from medical procedures and therapies without having to be manually restrained, sedated, or anesthetized. What children and youth with intellectual, developmental, and physical disabilities need most to benefit equally from modern medical care is a care provider with enough patience and motivation to arrange for or provide behavioral training in preparation for challenging medical procedures and health care routines. While this is challenging for family and medical caregivers, it is possible and often quite easy from a behavior analysis perspective.

4.7. SUPPORTING LITERATURE

The strategies and techniques described in this chapter have their origins in the fields of experimental analysis of behavior and applied behavior analysis, as discussed in the prior introductory chapters. Within this "behavioral" discipline, the principles of learning, behavior, and conditioning have been demonstrated to be effective in countless situations across children of all ages and developmental levels. During the 1960s, child psychologists began to move away from a more psychodynamic play therapy approach to adopt a "behavior modification" approach to psychotherapy that was based on these principles and focused on training parents to change their child's behavior. In this approach, what has now come to be called the "scientist practitioner model" was adopted. In this model each treatment provided must be tested in each case and, if not confirmed, revised based on the observational data and tested again until demonstrated

to be effective.[3] This empirical, behavior modification approach has resulted in numerous parent training books and manuals that can be helpful to parents, caregivers, and professionals alike who are tasked with managing the behavior of distressed and disruptive children.[4–8] Effective child behavior management strategies and parent training curricula for teaching them have produced an extensive empirical literature over the past three decades. One of the most productive and frequently used approaches has been called "parent-child interaction therapy."[9-10] An extensive list of references for this area can be found at the following Web site: http://pcit.phhp.ufl.edu/Literature.htm.

KEY CONCEPTS

- Behavior is determined primarily by three types of things: environmental antecedents, internal biological states, and social or environmental consequences.
- By observing and analyzing a child's behavior and applying basic behavior management procedures, caregivers can anticipate, prevent, or manage behavior problems associated with medical care.
- Children often are judged to be "noncompliant" when they don't understand the caregiver's verbal instruction or have not been given enough time to translate words into action.
- As a general rule, using the fewest and simplest words to instruct a child increases the chances that the instruction will be followed.
- Tasks that require a series of behaviors may need to be presented as a sequence of individual steps.
- A primary objective of child behavior management is to observe the child for examples of positive, desirable behavior and to give positive attention and preferred items or activities when that behavior occurs ("Catch them being good!").
- A powerful behavior management tool involves deliberate, strategic withholding of caregiver attention and preferred activities when problem behavior is occurring.
- A child's initial response to withdrawing or withholding previously provided reinforcement will be a temporary increase in the problem behavior before it eventually decreases ("It may get worse before it gets better").

- To effectively employ behavioral techniques, one must assess each child's preferences in order to select items and activities that are truly reinforcers.
- "Time-out" is an effective behavior management strategy only when it involves time-out from positive reinforcement.
- Negative reinforcement occurs when an unpleasant stimulus is removed after a target behavior and that behavior subsequently occurs more often.
- A child's distress behavior may be motivated by its escape or avoidance effect (allows the child to escape or temporarily avoid a nonpreferred situation).
- Escape-motivated behavior might be prevented in some situations through antecedent modification that reduces the amount of unpleasant stimulation.
- Escape-motivated behavior may be gradually extinguished by preventing escape.
- Escape behavior also may be decreased by providing a signal that allows the child to predict when the unpleasant stimulation will begin and end.
- Providing an alternative behavior that can temporarily stop the unpleasant stimulation may also decrease escape behavior (e.g., handing the nurse a break card to get a short break from discomfort during a medical procedure).
- Children and youth with intellectual, developmental, and physical disabilities need patient caregivers to provide or arrange for behavioral training to teach them how to cooperate and cope with unfamiliar and/or unpleasant medical care.

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Helping Young, Developmentally Delayed, and Highly Anxious Children Cooperate with Routine Physical Examinations

IN THIS CHAPTER

- This chapter presents strategies that can be implemented by parents, caregivers, and health care providers to facilitate child cooperation with medical examinations.

5.1. PATIENT POPULATION AND TARGET PROBLEM(S)

Routine medical evaluation and care are, or should be, common experiences for all children, beginning in infancy with well-child visits to monitor growth and development, to manage common childhood illnesses, and to administer required immunizations. All children receiving health care require periodic physical examinations. Cooperating with routine experiences such as a physician's touch or manual probing of the abdomen; ear, eye, nose, and throat examination; and temperature, heart rate, blood pressure, and reflex assessments can be difficult and frightening when experienced for the first time by young and/or developmentally delayed children. The child-caregiver interaction patterns that develop during these first medical experiences establish a history of learning, behavior, and emotion regulation that can have far-reaching effects. This chapter reviews common pitfalls that can occur during physical examination of any child and presents strategies that can be implemented by all parents, caregivers, and health care providers in order to facilitate child cooperation with medical examinations of any type.

5.2. ASSESSMENT PROCEDURES

It is always helpful to try to evaluate a medical experience from a child's perspective: when I go to the pediatrician's office, I am going to an unfamiliar place seeing things and people that are not a part of my familiar routine (including that funny-feeling crinkly paper they place on the exam table). A stranger touches me, picks me up, and puts things in my ears and mouth. I smell unfamiliar smells and hear unfamiliar sounds and voices. Even if none of these novel sensations are painful, they still may be experienced as aversive (uncomfortable, physiologically activating, and nonpreferred). Thus, the necessary ingredients for aversive conditioning, negative reinforcement, and conditioned anxiety are present. If the medical visit involves a greater ratio of aversive to reinforcing stimuli, a child will most likely display distress behavior (crying, screaming, kicking, squirming, clinging, retching, etc.), and if these behaviors allow the child to avoid or escape nonpreferred or aversive stimulation, they will be negatively reinforced and more likely to occur in the same or similar situation in the future. Furthermore, if conditioning of emotional arousal has occurred, then some of the seemingly benign or even positive stimuli may become conditioned aversive stimuli because they preceded and therefore have been associated with subsequent aversive stimulation in the medical context.

5.3. THOUGHTS TO GUIDE FAMILY CAREGIVERS AND HEALTH CARE PROVIDERS

A child's first visit to the pediatrician is typically his or her introduction to health care and may set the child's emotional development in this context on a positive or negative course. A parent, caregiver, or health care provider may question, "Why make such a big deal out of a child getting distressed during an exam or other medical care? Won't the child just get used to it with repeated visits or, if they don't come that often, just forget about it?" The answer, as in so many situations, is, "It depends." It depends on many things. Important variables that determine the nature of this introduction include child temperament, parent-child attachment, separation anxiety, fear of "strangers," child sensitivity to sensory experiences (e.g., unfamiliar sensations, discomfort or pain), and how parents and medical providers respond to child distress. Many of these variables have been studied extensively in their own right. For example, the behavioral and physiological

responses of infants to immunization pain have been studied and will be discussed further in chapter 6.

Entire research careers have been devoted to the study, classification, and effects of different profiles of child temperament and associated parent-child interaction patterns. For example, the "strange person, strange situation" paradigm, which involves temporary separation of a parent and child, has been used extensively in child development research on temperament and emotion regulation. An in-depth discussion of each of these variables and the associated research literatures is beyond the scope of this book. However, the existence of these extensive research literatures underscores the importance of these variables in child development, the complexity of child behavior in general, and their potential effects during medical care. The procedures and strategies recommended in this chapter require the investment of a little extra adult time, attention, forethought, and effort. They can, however, help a child develop skills for cooperation and emotion regulation that will serve them well in future health care situations. If a child is healthy and only needs well-child visits, the extra time and effort may seem too great. For children with serious and chronic health conditions, the wisdom of the investment seems obvious. However, all children will eventually need some type of health care, and taking the time to help healthy children gain the skills needed for cooperation, coping, and emotional self-regulation under stressful circumstances will be time well spent. Medical examinations are great opportunities for children to begin to learn important life skills. The information provided in this chapter can help the caregiver make the most of these opportunities.

5.4. SUPPORTING LITERATURE

A growing body of behavioral research supports the effectiveness of behavior analysis–based interventions for establishing child cooperation with health care examinations. Allen and Stokes[1] provided negative and positive reinforcement to typically developing children ages 3–6 using contingent escape, stickers, and praise. Their results indicated that reinforcement for cooperative behavior during practice and actual dental visits decreased the children's disruptive behavior.

A related study obtained similar results with three typically developing children ages 3–7 when brief escape (a break) from dental procedures was allowed contingent on intervals of cooperation.[2]

Stark and colleagues[3] provided distraction during dental visits to four typically developing children in the form of a poster and a story about what was depicted in the poster. They also provided positive reinforcement (prizes) if the children correctly answered questions about the poster and story at the end of the visit. Anxiety and disruptive behavior decreased for all four children using this intervention, but these improvements were not maintained for two of the four children.

Altabet[4] studied individuals with intellectual and developmental disabilities (IDD) who were fearful of and noncompliant with dental care. The study examined the effects of a systematic desensitization procedure adapted to address the needs of individuals with severe and profound mental retardation. The behavior of 35 individuals receiving dental desensitization was compared to that of 28 individuals that had not received any behavioral intervention. The results indicated that those receiving the desensitization intervention showed greater improvement in compliance with dental procedures than did those in the no-intervention comparison group.

In another study with adults with severe to profound IDD the investigators[5] assessed the effectiveness of in vivo desensitization and video modeling for increasing compliance with dental procedures. During the desensitization procedure, the dentist and a familiar behavioral staff member provided enthusiastic praise and encouragement, along with verbal and physical prompts during each step of a dental procedure task analysis. Only after the patient was relaxed and calm at one step were prompts provided to attempt the next step. This continued until all of the steps could be completed. Desensitization increased compliance for all five participants, but video modeling increased compliance for only one of three participants.

More recently, Cuvo and colleagues[6] evaluated a behavioral package to teach children ages 3–5 with autism spectrum disorders to cooperate with an eight-component oral examination. In this study a dental hygienist first performed a pretest during which the occurrence of compliance, escape/avoidance, aggression/destruction, protesting, and disruption were recorded for each step of the examination using a task analysis format. The results indicated that none of the participants were able to fully cooperate with the dental exam before behavioral intervention. After the baseline assessment, a behavioral intervention package was implemented, which included stimulus preference assessments, stimulus fading, distraction, extended baseline exposure to aversive stimuli, video priming (filmed modeling shown

at home daily), prompting (i.e., verbal instructions, photo, gestural, physical), differential reinforcement, and escape extinction. The study results documented the efficacy of the intervention procedures for increasing the children's compliance with the oral examination conducted by a behavior analysis graduate student in an analogue setting at a children's autism center. The successful behavioral effects also generalized to the actual oral examination conducted by a dental hygienist in a dental clinic. Furthermore, training compliance to some steps of the oral examination routine generalized to other untrained steps for some participants. The effects were also maintained for up to one month after training was completed. The authors pointed out that more research is needed to dismantle the intervention package, to determine if all of the treatment components are necessary, and to determine the willingness of dental staff to adopt these behavioral procedures. Nevertheless, the results are a clear demonstration of the effectiveness of applied behavior analysis for improving the ability of children with developmental disabilities to cooperate with health care procedures.

Other examples of behavior analysis being used to improve child cooperation with various types of health care examinations have been published intermittently over the past three decades. For example, in one case study[7] task analysis, gradual exposure, and positive reinforcement for cooperation were employed to successfully desensitize an autistic girl to gynecological examinations.

Other investigators[8] conducted a series of single-participant experimental design studies in which environmental correlates of self-injurious behavior were systematically examined and subsequently used as the basis for treatment. In this series of cases, one of the subjects exhibited self-injurious behavior that occurred in response to medical demands (i.e., physical examinations). For one 16-year-old with moderate intellectual disability and self-injurious behavior, treatment was conducted during simulated physical examinations and included escape extinction (continuing with the exam despite the self-injurious behavior) combined with reinforcement for tolerance of an examiner touching or pressing on various body parts required for physical examinations. The results showed that the treatment was successful for both increasing cooperation with the physical exams and eliminating self-injurious behavior. Furthermore, these effects ultimately transferred across therapists and physicians.

Another team of investigators[9] studied the effects of reinforcing compliance with prompts to engage in a high-probability behavior on a toddler's

subsequent compliance with prompts to engage in a low-probability behavior (cooperation with a medical procedure). The child was a 22-month-old with short bowel syndrome, developmental delay, and severe self-injurious behavior. He also was noncompliant during necessary care of an indwelling central venous catheter (c-line). He interfered with the routine care of the c-line by such actions as turning away, touching the sterile site, pulling out the c-line, and kicking. A behavioral momentum strategy was combined with escape extinction (response blocking) because the child's behavior was life threatening (could have caused a blood infection). The results indicated that providing reinforcement for compliance with high-probability behavior (easy tasks) combined with escape extinction using response blocking for disruptive and dangerous behavior increased the child's subsequent compliance with behavioral demands required for safe care of his c-line. This case highlights how behavior analysis interventions can make a major contribution to a child's medical care by decreasing or eliminating a potentially life-threatening behavior problem (infecting or pulling the c-line out of his heart).

In another recent study[10] children with autism were taught to comply with a 10-component physical examination. First, a physician assistant conducted a pretest examination. Data on compliance were recorded using a task analysis of the steps in the examination. An assessment was conducted of the number of steps of the examination on which there was noncompliance. This assessment identified skill deficits and escape from aversive stimuli as determinants of noncompliance. Based on this assessment, a package of behavioral training procedures was implemented, which included a stimulus preference (reinforcer) assessment, priming (filmed modeling), various types of prompts, desensitization to aversive stimuli, shaping, escape extinction, and differential reinforcement of other behavior. Results indicated that this package intervention was effective, and the behavioral effects generalized from the training center setting with a trained behavior analyst to a medical clinic with a physician assistant as the examiner. For some of the participating 3- to 6-year-old children with autism spectrum disorders, there was generalization of compliant responding to examination procedures that were not specifically trained. Improved responding also was maintained at one-month follow-up. However, this study did not assess whether the effects of the training package generalized to the children's regular health care providers in their natural setting.

5.5. CASE EXAMPLES

In a recently published study[11] two children were trained to cooperate with routine medical care for cystic fibrosis (CF). The medical care included throat culture specimens obtained quarterly in an outpatient CF clinic. Obtaining a throat culture from these anxious and uncooperative children was difficult for the children's pulmonologists because of child emotional distress and escape/avoidance behavior that disrupted specimen collection. In these cases, a behavioral therapy protocol was employed including gradual exposure and systematic desensitization to treat the behavioral distress of the two CF patients (ages 4 and 6) during routine throat cultures. The behavioral interventions were implemented first during mock procedures and subsequently during actual specimen collection (see fig. 5.1).

After five months of unsuccessful attempts by the medical staff to obtain throat culture specimens, Patient A attended three outpatient behavioral training sessions over a one-month interval. In the first two sessions, Patient A exhibited distress but eventually tolerated placement of the throat culture swab on the back of the tongue. The third session occurred at the child's scheduled CF clinic visit. During this visit, the physician successfully obtained a throat culture specimen with little patient distress.

For Patient B, the medical professionals were unable to obtain the necessary throat specimens for over 10 months. Thereafter, the patient was provided with six behavioral training sessions over a two-month interval. Five sessions were devoted to direct behavior modification and caregiver training. These sessions taught the caregiver to implement a consistent routine during the medical procedure, to use differential social reinforcement, and to provide the child access to preferred activities contingent on successful task completion. During these sessions, the child also was taught to use distraction and visual imagery as coping strategies during specimen collection. The fifth session took place in a typical examination room in order to facilitate stimulus generalization to the actual CF clinic setting. The remaining sessions were conducted during routine CF clinic visits. The behavior therapist assisted the physician and caregiver with implementing the behavioral routine and prompting the child to use distraction and imagery. The effectiveness of this behavioral intervention demonstrated with the first child was replicated with the second. At the time the study was published, the intervention continued to be effective at one-year follow-up. The behavioral intervention was regarded by the therapist

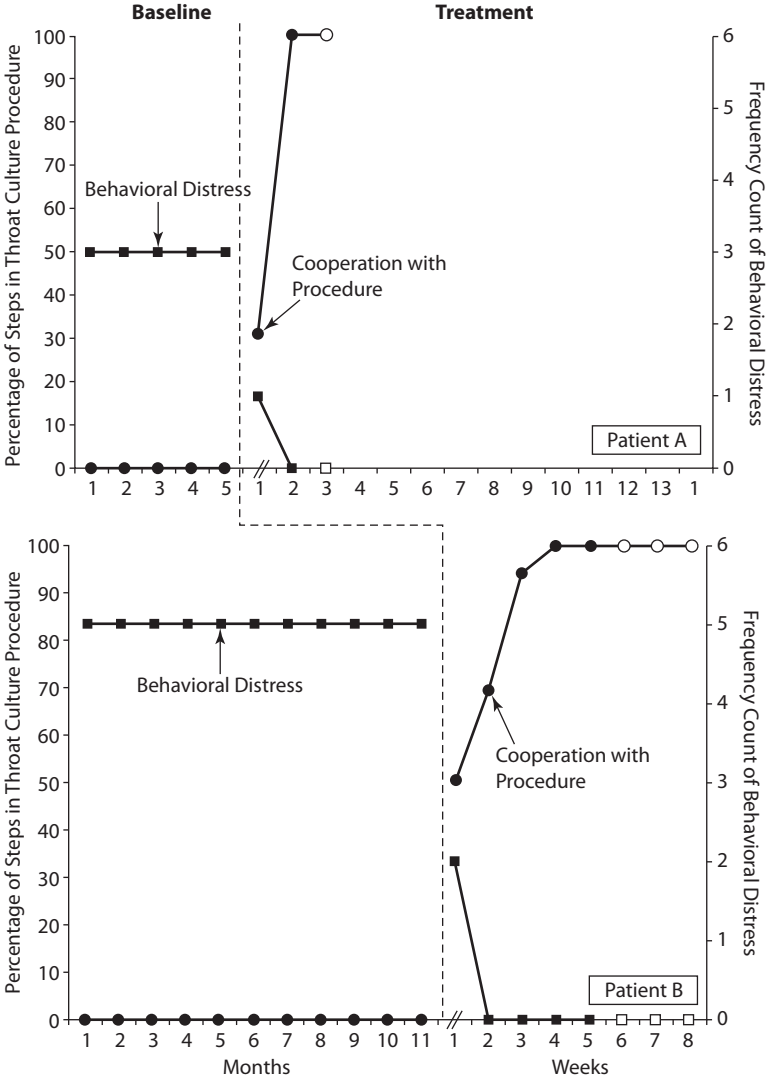

Figure 5.1 Treating behavioral distress and noncompliance with throat culture specimen collection in children with CF. Prior to behavioral intervention, Patients A and B exhibited elevated behavioral distress and poor cooperation. After two weekly therapy sessions, the patients no longer exhibited behavioral distress and were able to cooperate during the procedure. The closed symbols indicate mock medical procedures, and open symbols depict actual specimen collection during a CF clinic visit. *Source*: Ward, C.M., Brinkman, T., Slifer, K.J., & Paranjape, S.M. (2010). Using behavioral interventions to assist with routine procedures in children with cystic fibrosis. *Journal of Cystic Fibrosis*, *9* (2), 150–153. Reprinted with permission from Elsevier BV.

and medical team to be simple to implement and easily transferred from mock procedures to actual specimen collection.

In patients with CF, routine throat cultures are essential to screen for chronic bacterial infection because of its impact on clinical management of lung disease. These cases illustrate how behavior analysis–based methods can be used to overcome behavioral barriers to essential medical care in young children.

5.6. INTERVENTION PROCEDURES

What follows is a discussion of some strategies that can be used by caregivers and health care providers to facilitate child adjustment to routine medical care. Recognizing these variables and using the strategies discussed below may decrease child distress, increase cooperation during routine physician visits and examinations, and thus prevent inadvertent aversive conditioning that could impact the child's adjustment to and acceptance of health care services for years to come.

The following intervention strategies have been helpful in reducing child distress during routine medical care:

1. *Create a "child-friendly" environment*. This can be achieved by furnishing the patient waiting and play areas and exam and procedure rooms with colors, artwork, music, and activities that are attractive to children. The overall goal is for the doctor's office or clinic to be a place to which the child is attracted and that he or she finds interesting and reinforcing. Even if there will be an uncomfortable experience, if it is both preceded and followed by opportunities to participate in reinforcing play activities, the child's overall experience will be more positive, and he or she will be more likely to return without protest the next time a medical visit is required.

2. *Whenever possible, get down on the child's level of the physical environment*. So much of the physical environment in our society is designed for the comfort and convenience of adults. This is, of course, justifiable because the vast majority of us are adults, and as we get older and often less fit and flexible, comfort and convenience become increasingly important. On the other hand, environments such as day care, preschool, and pediatric settings, which exist to meet the needs of children, should be designed with their comfort and worldview in mind. In addition, professionals who care for children should be willing and able to get down on their knees or sit down low when interacting with young, disabled, or anxious children.

Even adults of average stature can seem intimidating when standing over a child, particularly if the child is required to sit, lie down, or be in some other vulnerable position when receiving medical care.

3. *Use a child-friendly tone and volume of voice*. Interpersonal characteristics such as the professional's tone and volume of voice are important for a child's comfort and coping. A loud, abrupt, harsh-sounding voice, although not intended to be aversive, can startle and frighten a child who is unfamiliar or not expecting this type of stimulation. Providing a calm, neutral, and modest-volume verbal warning to the child before touching his or her body during an examination is highly recommended. Even for a preverbal child a simple verbal warning such as saying "get ready" or "touch" before making physical contact is helpful in keeping children calm. This is especially important for children with developmental disabilities who are particularly sensitive to certain types of touch (those who are described as tactile defensive).

4. *Use simple and direct verbal instructions*. For health care professionals who read, think, converse, and write using advanced language skills and vocabulary, it is easy to forget that children, especially the very young and those with intellectual or developmental disabilities, don't speak the same language that we do. Adjusting one's vocabulary and sentence complexity to a developmentally appropriate level can have a positive impact on child compliance during a medical examination or procedure. As a general rule, the fewer words, the better. Instructions should be given using the simplest language possible, and proceeding one step at a time will help ensure that the child comprehends what he or she is being instructed to do. Busy adults who are feeling stressed, as caregivers and health care providers often are, may become impatient if the child does not immediately comply. Their response is often to repeat the instruction with increasing volume, frequency, and urgency. If there is more than one caregiver or provider, they may all speak at once, presenting overlapping and competing instructions. Under these conditions a child is likely to become increasingly anxious and confused and may become too distressed to listen to or comprehend what is being said. Children who are very young, anxious, and/or have developmental or learning difficulties are especially vulnerable to distress with too-frequent, loud, or complex instructions, particularly if coming from several speakers simultaneously. For these reasons instructions should be given by a single adult, in a calm, neutral tone, using simple language at a conversational volume, and prompting one step at a time. Instructions

should be presented at a pace that allows between 5 and 10 seconds for the child to respond before repetition or presentation of the next step in the examination or procedure.

5. *Reinforcement of tolerance and coping*. As in any other behavior management recommendation, providing frequent positive reinforcement for appropriate behavior cannot be overemphasized. Any occurrence of following an instruction, cooperating, or decreasing distress should be reinforced even if the occurrence is partial and imperfect. Reinforcement includes descriptive praise (e.g., "Bobby, you did such a good job stepping on the scale"; "Thank you for holding still and being quiet while I listened to your heart"). In addition, other types of positive reinforcement involving tangible, edible, and token reinforcement may be provided contingent on cooperative behavior during a physical examination if it does not disrupt the necessary medical assessments. Such strategies will be discussed in more detail below in relation to task analysis and graduated exposure to stressful aspects of the examination.

6. *Timing, pace, and graduated exposure*. Very young children and those with intellectual or developmental disabilities can be surprisingly successful at cooperating with medical care. However, allowing them time to learn is critical. Children need to have the opportunity to learn about the physical sensations they will experience and to master basic skills such as instruction following, holding still, and managing their anxiety or fear. Surprisingly, they often require little more time than an anxious adult but frequently are not given the same patient and courteous treatment as adults.

There are probably many reasons why children are often not treated with the same patience and consideration as adults. Some of these include negative opinions and beliefs about the child's capabilities and motivation, medical provider and caregiver discomfort with even mild child distress, and the financial and institutional pressures for efficiency that pervade most medical settings. These pressures are especially formidable in pediatrics, where reimbursement rates are low and caseloads are high. Time pressure is acute at university-affiliated teaching hospitals, where staff may have academic and research demands on their time in addition to their patient care responsibilities. Time pressure is prominent in diagnostic testing situations requiring expensive equipment that is financed and funded via high utilization of the equipment or laboratory. Nationwide concerns about rapidly increasing health care costs contribute to a culture that demands high patient volumes and efficiency in rendering care. This demand for health care providers to complete their tasks rapidly is diametrically

opposed to what is needed by a child to cooperate without distress or disruptive behavior, and to avoid sedation, anesthesia, or restraint. Children need time to learn and practice cooperation and coping skills.

One of the premises of this book is that with forethought and a systematic approach to preparation and training, it is possible to provide children the time they need to learn to be successful during medical care. Of course, medical emergencies preempt such opportunities, but except for in emergency departments, true emergencies are surprisingly rare. Most appointments and procedures are scheduled well in advance, and children and families spend considerably long periods in waiting rooms. This is time that can be used productively by behaviorally trained therapists to work with these families to teach child cooperation and coping skills.

Not only do children need time to learn and practice their skills, but they also need a physical space in which to do so. Space, of course, is another resource that is typically at a premium in medical settings. All such spaces have costs for rent, overhead, and maintenance, which can be an impediment to providing appropriate environments in which child training for medical care can be conducted. However, with creative use of already-funded clinic space during low utilization times, appropriate billing for behavioral health services, and philanthropic donations, such environments can be located or created.

Furthermore, many parents, particularly those of children with chronic conditions, are quite willing to bring their child to behavior therapy sessions at times when no actual medical care is scheduled so that the child and parent can work with a therapist in anticipation of and preparation for impending medical care. These sessions can be scheduled when actual medical environments are available for "practice sessions" or can be conducted in a nonmedical clinic setting (psychologist's office, mental health outpatient clinic, Child Life suite, or even in the home). In such nonmedical settings it will be necessary to set up simulated or "mock" medical procedures and equipment. This can range from the very inexpensive, such as make-believe games and toy doctor's kits, to collections of actual medical supplies (those that have been "decommissioned" or are inexpensively available for home use). For some types of procedures such as magnetic resonance imaging (MRI) or radiation therapy it is possible to design and fabricate or to purchase simulation equipment. This can be improvised (e.g., a playground tube slide tunnel for a mock MRI scanner, a TV remote control inside an examination glove to simulate a transducer for a sonogram) or purchased (blood pressure cuff, tongue depressors, or digital

thermometer) from a pharmacy or medical product supplier. Philanthropic or other public or private sector grant funding can sometimes be obtained to purchase this type of material and develop a child training environment.

The combination of time, space, and simulated medical equipment along with the availability of a behavior therapist can make it possible for children to be gradually exposed to and taught about the medical care with which they need to be able to cooperate. Gradual exposure can take one or many training sessions depending on the child's age, developmental level, temperament, anxiety level, and learning history. As a general rule, those who are very young, have IDD, or have been traumatized by past painful or uncomfortable procedures will require more training sessions. They will need more gradual exposure and more rehearsal and coaching of cooperation, movement control, and specific coping skills. For those children with chronic conditions who will require frequent medical procedures and care for life (or at least the foreseeable future), the time spent on this type of training is an investment that will pay off in terms of safer, more efficient, and less distressing medical care in the long run. Even for those children who are expected to get well and require no more than typical medical care in the future, the investment is still worthwhile, if it can help them develop positive attitudes and skills that will increase their likelihood of seeking and using medical care appropriately to maintain good health across their life spans.

Gradual Exposure Therapy

The technique of gradual exposure is derived from two fields. The first is as a behavior therapy technique that has been used successfully by psychologists and behavior therapists to treat specific anxiety disorders such as simple phobias (spiders, snakes, heights), social phobias, school avoidance, and agoraphobia (fear of going out to public places). The technique involves gradually increasing how close the patient is to the feared object (physical proximity) and the length of time (duration) the patient is in contact with the feared object or situation. Physical proximity and duration of exposure can be adjusted using visual imagery or through direct real-life ("in vivo") contact. The exposure is graded and paced according to the patient's anticipated and actual distress at each step. The therapist coaches the patient through the progressive exposure such that the patient is challenged to tolerate increased levels of anxiety but never overwhelmed by anxiety. Exposure is not forced but encouraged, and the patient agrees in

advance to the exposure objectives of each therapy session. He or she is taught relaxation strategies or other coping skills to help tolerate the exposure and achieve the therapeutic objectives both within and across therapy sessions. The therapist and/or patient plan and administer positive reinforcement for achieving planned objectives or approximations of these objectives. To be maximally effective, the exposure should moderately elevate the patient's anxiety and the patient should be assisted in maintaining the exposure at that level until he or she perceives a noticeable decrease in anxiety and can conclude the session with success and positive reinforcement. This process is a critical element in preparing children for physical examinations and routine medical care, as well as the more complex or highly technological health care procedures and regimens discussed in subsequent chapters.

Errorless Learning

The second field from which gradual exposure derives is that of the education and training of individuals with IDD. In this field, as well as some types of vocational and military training, complex tasks are broken into their component steps (task analysis), and each step in the sequence is taught one at a time beginning with either the initial step (forward chaining) or the final step (backward chaining). Teaching one step at a time allows the learner to concentrate on and master a manageable challenge to his or her physical skill, as well as managing any performance anxiety associated with that step or specific behavior, before attempting the next in the sequence or performing several steps in rapid succession. Ultimately training and rehearsal trials continue until the entire task sequence has been mastered and can be completed independently.

As will become evident below, the use of simulated medical procedures that have been task analyzed for teaching, along with exposure therapy and rehearsal of coping strategies, will be a recurrent theme in most of the remaining chapters of this book. To begin applying this approach, we will turn to the task analysis of a medical visit for a physical examination presented in table 5.1.

Obviously many variations of the task analysis in table 5.1 may apply depending on the symptoms being assessed and who does the examination. Furthermore, various steps may be added or deleted, and steps may be broken down into still smaller steps if necessary to obtain cooperation while keeping the child calm. In addition, the sequence of steps can be arranged

TABLE 5.1 Task Analysis of a Physical Examination

STEP #	Required Behavior	Notes on Performance
1	Child walks from the waiting area toward the examination room accompanied by parent.	
2	Child walks into the examination room and sits on parent's lap in a chair.	
3	Child remains calm as nurse or doctor enters the examination room.	
4	Child gets down from parent's lap and walks to the scale for weighing when instructed by nurse.	
5	Child steps onto scale with both feet when prompted by nurse.	
6	Child walks back and sits on parent's lap when instructed to do so.	
7	Child opens mouth and says "ahh" when prompted and allows doctor or nurse to look into mouth and throat using scope or light.	
8	Child looks at and tracks light with eyes when prompted.	
9	Child allows doctor or nurse to look into both ears with scope.	
10	Child allows temperature to be taken with electronic thermometer inserted in ear for five seconds.	
11	Child allows blood pressure cuff to be placed on upper arm.	
12	Child assists nurse by pressing the "start" button on automatic blood pressure machine.	
13	Child remains still and calm as blood pressure cuff inflates, reading is taken, and cuff is deflated.	
14	Child assists with the removal of blood pressure cuff.	
15	Child follows instructions to squeeze doctor's hand and to push and pull with hands and legs for strength assessment of upper and lower extremities.	
16	Child allows doctor to listen to heart with a stethoscope and remains quiet when prompted.	
17	Child inhales and exhales as modeled and prompted by doctor who assesses lung and airway sounds with stethoscope.	

into an individualized hierarchy beginning with the least challenging or distressing for any given child and progressing toward the most challenging or distressing. The pace of presentation of instructions and prompts can then be adjusted to give the child adequate time to respond. Instruction following or attempts to do so should be praised and reinforced with affection, brief play, or tangible reinforcement as each step is completed or at least attempted. As mentioned previously, the importance of providing positive reinforcement for positive behavior can hardly be overemphasized when teaching children new skills and managing their behavior.

Behavioral Momentum

This strategy borrowed the concept of "momentum" from physics.[12] "Behavioral momentum" refers to first presenting easy task demands that the individual is likely to cooperate with first before presenting more difficult demands. As compliance with easy tasks is demonstrated, it is positively reinforced by the therapist. Consequently, the probability of the individual's subsequent compliance with more challenging task demands increases. By obtaining and reinforcing compliance with easy tasks, the chances that the individual will comply with subsequent more difficult demands are systematically increased. In the pediatric examination shown in table 5.1, sitting on the parent's lap or the child opening his or her mouth and saying "ah" are easy tasks for most children for which there is a high probability of compliance. By presenting and reinforcing compliance with these steps first, the chances that the child will comply with more difficult demands (allowing temperature probe in the ear or placement of the blood pressure cuff) will likely be increased. However, which tasks are more or less difficult varies across children. Therefore, the presentation hierarchy must be individualized for each child.

While the nurse or physician in everyday practice is unlikely to develop an individualized hierarchy for each patient, keeping in mind the concepts of task analysis, graduated exposure, and behavioral momentum might be considered when developing office or clinic routines. A compromise between procedural efficiency and child comfort and learning may be a reasonable objective. However, if a child has a great deal of distress during routine procedures, then arranging for mock procedures conducted by a behavior therapist is warranted. The therapist will be able to develop an individualized exposure hierarchy and apply it during practice sessions,

which will be a helpful investment in the child's coping and future adjustment to medical care.

Counterconditioning

As discussed in chapter 2, counterconditioning involves selection of activities or techniques that can induce a relaxed state and can be used to increase the chances that a child will approach an item or situation that he or she was previously motivated to escape or avoid. Once the child is engaged in a relaxing activity, then a more stressful or less preferred stimulus can be introduced. With this pairing of anxiety-inducing stimuli with those that have already established a relaxed state, the negative effects of the anxiety-inducing stimulus can be decreased over time. This technique can be integrated into the medical situation by engaging the child in a preferred, relaxing activity in the examination room and then presenting challenging task demands and nonpreferred or feared medical stimuli gradually as described above in the discussion of graduated exposure.

Choice and Control

Behavior analysts have studied the reinforcing effects of an individual being able to choose among possible responses and of being able to control aspects of one's physical environment. Research in this area has adopted the term *behavioral economics*. To present this concept simply, the probability of one behavior occurring versus another is determined by a dynamic balance between how effortful the behavior is and the reinforcing value of its consequences. For example, one might be willing to walk a mile for $10 or five miles for $50, but not be willing to walk 10 miles for $50. Children also are affected by the conflict between how difficult a task is and the amount of reinforcement the behavior will produce. In medical situations positive reinforcement can be arranged such that cooperation with more difficult or uncomfortable procedures results in a greater amount of reinforcement (a prize of greater value or longer access to a preferred activity) than cooperating with an easy task or procedure. When possible, choices also can be incorporated into the medical routine by including some steps that the child may safely refuse, allowing the child to choose between two equally acceptable ways of undergoing a procedure (sitting in mother's lap versus lying on the exam table) or to choose the order of procedures (blood pressure check or temperature taken first). In clinical practice, allowing the

child to make choices often decreases child distress and increases cooperation.

Distraction

There is considerable research evidence that distraction can be effective in decreasing behavioral distress and the perception of discomfort or pain during medical procedures. As the theory goes, each individual has a limited capacity to attend to sensations from internal and environmental stimulation. If a child is presented with a salient and preferred form of stimulation (e.g., playing a multisensory computer game) when exposed to an uncomfortable stimulus, he or she will be less aware of the uncomfortable sensation. Therefore, with sufficient distraction a child will be able to tolerate more intense negative stimulation and/or tolerate it for a longer duration. Research has shown that interactive distraction that requires the individual to cognitively process and make a response to the distracting activity appears to be especially effective in increasing tolerance and decreasing distress behavior.[13–14] Furthermore, preferred activities used to establish relaxation and approach behavior for counterconditioning may also serve to distract a child from uncomfortable sensations during a medical examination or procedure. Singing, listening to recorded music, counting, word games, visual imagery, conversation, videotaped movies, interactive storybooks, electronic toys, computer games, and virtual reality goggles all have been used successfully to distract children during medical procedures, thereby decreasing distress and pain perception and increasing cooperation and coping.

Escape Prevention and Guided Compliance

Thus far we have emphasized the goal of integrating reinforcing, relaxing, and distracting activities into medical care to make the experience as positive as possible. Using mock procedures to allow for gradual exposure and teaching coping skills can, in most cases, result in successful completion of the medical exam or procedure. However, there are occasions when, despite these precautions, children become distressed enough to attempt to avoid or escape the procedure. The most common escape/avoidance behaviors (of which there are many) include crying, pushing away, blocking with hands, head or body turning, hitting, kicking, running away (leaving the examination room), and attempting to verbally bargain to avoid the

procedure. This type of behavior is more likely if the procedure is uncomfortable or painful and the child has experienced it before, particularly if the child had a traumatic experience with this or a similar procedure in the past. Mock procedures, exposure therapy, counterconditioning, and/or distraction may be critical for helping a child overcome conditioned anxiety resulting from past traumatic medical experiences. However, even during the initial steps of the exposure hierarchy the child may require physical blocking and gentle guidance to cooperate. Of course, caution is required to prevent inadvertent injury to the child, caregiver, or service provider. The least amount of physical contact should be used, only that which is required to prevent escape, block aggression, and achieve enough success to positively reinforce an approximation of compliance. Failure to achieve this minimum degree of cooperation means that the child has been able to successfully avoid or escape an aversive or nonpreferred situation, and his or her distress behaviors will have been negatively reinforced, thereby making these behaviors more likely to recur in the future.

Progressive Guided Compliance

To obtain child compliance, it is recommended that the therapist begin with a verbal prompt using the minimal number of developmentally appropriate words as discussed earlier in this chapter. The child should be allowed a minimum of five seconds but no more than 10 seconds to respond. If the child does not comply within this time frame, the verbal prompt should be repeated along with a physical demonstration (modeling) of the prompted behavior. If the child has not initiated compliance within another 10 seconds, the therapist should again repeat the verbal prompt while using the least amount of physical contact to guide the child to complete the prompted behavior. Even if physical guidance is required, positive reinforcement (praise, brief access to a preferred toy or activity, etc.) should be provided contingent on completion of any portion of the prompted behavior. This sequence of verbal prompting, modeling, and physical guidance has been called "three-step guided compliance" and has its origin in research on teaching and managing the behavior of individuals with intellectual or developmental disabilities. It bears repeating that even when children are distressed and require physical guidance to complete a procedure or a step within a procedure, they should be provided with positive reinforcement for tolerating and coping with a nonpreferred

event. At minimum, the child should receive praise for "getting through it," "being brave," or being "a hard worker."

Extinction of Classically Conditioned Anxiety

An additional tactic for helping children who have conditioned anxiety to medical stimuli is to expose the child to the setting on occasions when no procedures are required and allow the child to experience preferred activities or events in this setting in the absence of any aversive stimulation. For example, the child could be allowed to play in the pediatrician's waiting room, visit with the office staff and nurse, and, if possible, briefly visit the pediatrician and receive a greeting, hug, or handshake and receive a small treat or trinket. The goal is to associate the people and stimuli in this setting with positively reinforcing events. Thus, the medical setting is less likely to be one that the child associates with negative stimulation only.

Putting It All Together

In the Key Concepts box at the end of this chapter an outline is provided that should be helpful for orchestrating behavioral training to assist children in cooperating with a routine medical exam or medical procedure. As will become clear in the chapters that follow, these strategies also will apply to more complicated, demanding, or invasive procedures as well.

5.7. SPECIAL CONSIDERATIONS AND CHALLENGES FOR CHILDREN AND YOUTH WITH SEVERE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND SEVERE BEHAVIOR DISORDERS

Many of the studies described in this chapter were conducted with individuals having varying degrees of IDD and behavior problems, and the associated behavior analysis–based techniques have been shown to be effective with this population. It should be pointed out that there are individuals with very severe IDD and behavior disorders who require medical examination and care and present a special challenge even for highly trained and specialized behavior analysts. This includes those who are dangerously self-injurious, aggressive, and/or physically destructive. Use of behavior techniques with this population is appropriate, but procedures

to prepare these individuals for medical care must be considered within the broader scope of treating their existing, often long-standing and severe problems with learning and behavior across all domains of their lives. Children and youth of this type can learn to cooperate with physical exams and other types of medical care, but it requires much more time and effort and the direct involvement of highly trained professionals.

For children who cannot communicate verbally, more complicated functional assessments or functional analyses[15] are needed to determine the social and environmental variables that motivate severe behavior problems. Systematic observational stimulus preference assessments are needed to determine motivating items and activities that can be used to teach alternative and cooperative behaviors. More restrictive behavioral and environmental interventions are needed to manage dangerous behavior and to keep the individual and others safe while these assessments are conducted and during the testing and revision of individualized procedures to decrease dangerous and disruptive behavior and to teach more appropriate behavior. In many cases, these assessments and subsequent intervention protocols require many daily sessions with behavioral professionals under highly controlled conditions in order to be tested, refined, and ultimately successful. In the meantime, urgent medical examinations or procedures may need to be conducted using temporary physical restraint, sedation, or anesthesia. For this population, being able to cooperate and cope with medical care is not impossible, but it is a long-term undertaking that requires the guidance and services of professionals trained in behavior analysis.

KEY CONCEPTS

1. Identify reinforcing items or events for the child.
2. Conduct a task analysis of the behavioral steps in the examination or procedure to be completed.
3. Identify a medical setting or create a simulation of the procedure to conduct practice sessions.
4. Expose the child to the first steps of the task analysis to assess the child's level of distress and escape/avoidance behavior.
5. Discontinue the assessment as soon as it is clear that the procedure could not be performed.
6. After a brief break or at the next session, introduce into the medical setting an activity that is preferred, relaxing, and distracting for the child.

7. Allow the child to engage in the preferred activity for 5–10 minutes or as long as necessary to establish a relaxed state.
8. While the child is engaged in the relaxing activity, begin to present the initial steps of the task analysis and praise the child for any cooperation and for continuing the preferred activity.
9. Moving at a pace that allows the child to remain calm and to be successful, gradually continue to present the sequential steps of the task analysis.
10. When feasible, the steps in the task analysis should be presented progressing from the least to most distressing.
11. Proceed through the hierarchy at a pace that challenges the child (mild to modest evidence of distress) but does not overwhelm the child's ability to cope.
12. If avoidance or escape behavior is observed, use three-step guided compliance to obtain enough compliance to allow for its positive reinforcement.
13. If guided compliance is required to obtain partial compliance, return to the previous step and reinforce unassisted compliance.
14. Any individual session should be concluded on a successful note (unassisted compliance should be reinforced), and the child should leave the situation in a relaxed, happy state.
15. Once the child can cooperate with the entire task analysis with no more than minor distress, the routine should be moved to the medical setting where the actual examination or procedures will take place.
16. Gradually introduce the medical provider into the task analysis routine, and when the child appears able to cooperate with the actual examination or procedure, the provider should conduct the necessary steps while the caregiver and therapist coach the child to engage with the preferred and distracting activity.
17. Provide the child with praise and positive reinforcement for successful cooperation and coping.

Note: The parent or caregiver should be taught to participate in this therapy sequence by providing positive reinforcement for cooperation and coping

and by coaching the performance of coping responses (performing a distracting activity, deep breathing, or visual imagery) as prompted by the therapist. The timing and degree of parent involvement should be guided by the therapist based on what appears to facilitate versus disrupt child cooperation and coping.

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Helping Children, Parents, and Medical Caregivers Cope with Child Distress and Discomfort during Immunizations

IN THIS CHAPTER

- Information is presented about the special significance of routine immunizations that are almost universally experienced by young children the world over.
- The effects of these early pain experiences on a child's physical, behavioral, and emotional development are reviewed from the research literature.
- Pharmacological, physical, environmental, and behavioral interventions for immunization pain and distress that are supported by research are reviewed, particularly those involving topical anesthetics and distraction techniques.
- Suggestions for employing these pain interventions are presented in order to encourage their use in pediatric settings.

6.1. PATIENT POPULATION AND TARGET PROBLEM

Routine immunizations are an essentially universal experience of infancy and early childhood. However, immunizations have special significance because for typically developing, healthy children, immunizations are the child's earliest experience of iatrogenic pain. Given that in the United States the recommended childhood immunization schedule calls for up to 20 injections within the first 18 months of life,[1] special consideration must be given to the emotional significance of, timing of, and preparation for these early painful experiences. In addition, pharmacological, behavioral, and

cognitive-behavioral interventions that may decrease anxiety, pain, and behavioral distress and increase coping and recovery time for immunizations are available, and though widely known among pediatric psychologists and pediatric pain specialists, they are not widely used in pediatric primary care practices.

Does a child need advanced warning that she or he will be receiving an injection? If so, what should be said, and how far in advance? Thirty years ago it was widely believed that infants, particularly neonates, did not experience pain as acutely as older children and adults because of their immature neurological system, and in any case, even if they were to briefly experience intense pain, it was thought that they would not remember it because of their lack of a mature capacity for memory. These beliefs were prevalent especially for preverbal children because their subjective pain experience could not be easily assessed and their behavioral distress could be attributed to other causes such as fear or separation anxiety. These notions are still common among some health care professionals. However, among pediatric pain specialists it is understood that infants experience pain much like adults and possibly more intensely.[2–6]

6.2. ASSESSMENT

This chapter reviews many promising pharmacological, behavioral, and cognitive-behavioral strategies that appear to be helpful for reducing immunization pain and distress in children. Randomized controlled trials (RCTs) help us to identify the interventions that appear to have the greatest effect on the greatest number of children. However, matching specific interventions to specific children according to their ages, temperaments, and learning histories (behavioral and medical) is an essential part of clinical practice. Assessing which interventions are most helpful to individual children is a necessary part of ongoing individualization of care. The various types of interventions discussed in this chapter make up the current "toolbox" from which parents and health care professionals may choose when developing an individualized pain and distress management plan for young patients undergoing immunizations. However, the only way to determine what works for your individual child is to use the information in this chapter to select an intervention or combination of interventions that seems to best match your child and situation and that parents and health care providers agree to implement. Any intervention should be given a fair

trial, remembering that behavioral interventions require learning and cannot possibly be completely effective the first time they are tried. On the other hand, if you have given an intervention a fair try over a few consecutive occasions and it is not helpful, then it should be discontinued and an alternative approach selected and tested.

6.3. INFORMATION TO HELP FAMILY CAREGIVERS AND HEALTH CARE PROVIDERS COPE

No one likes to think of themselves as someone who hurts or upsets little children. Yet that is what nurses and pediatricians are called on to do and family caregivers to allow to happen when children get immunization injections. Of course, it helps to know that this brief pain serves the greater purpose of preventing health- and life-threatening communicable childhood diseases. Another way to feel better about causing this pain is for practitioners to decide what pain and distress management intervention strategies they will adopt in their practice and for caregivers to decide what interventions they will request and help to implement with their child. For example, one might choose the following procedures:

1. Use topical anesthetic applied in advance according to manufacturer instructions to the injection site(s).
2. Provide developmentally appropriate interactive toys for distraction (e.g., electronic games, push-button books, bubbles, or a pinwheel to blow) which the child can use in anticipation of, during, and after the injection.
3. Conduct the injection in a specific, separate, and prominently identified location (unique color or décor, dedicated procedure room, etc.).
4. Verbally direct and redirect the child's attention to the distraction activity during the procedure.
5. Provide quiet praise and a small reward for cooperation and coping with the procedure (even if the child whines, cries, or yells).

By adopting and consistently implementing a set of procedures that are supported by the available research literature, one can at least know that something reasonable was done to try to prevent hurting and potentially traumatizing the child. Even if your selected intervention is not fully effective, you can take some comfort in knowing that you took the time and

expended the effort to try to make the child as comfortable as possible. It is also helpful to know when a child and parent may need professional behavioral or psychological services. The child may be distressed to a greater degree and for a longer time than children his or her age typically are in the same circumstances. He or she may attempt to avoid or escape the injection by pushing away or hitting. A parent may have difficulty refraining from loudly expressed, angry-sounding scolding. Another parent might bargain with the child, repeatedly allow the child to avoid the procedure or cry, or apologize repeatedly to the child. If these signs occur on multiple occasions, it is probably appropriate to suggest and provide referral information for a behavior analyst or behaviorally trained pediatric psychologist.

By providing the above-suggested basic preventive procedures and allowing time in your daily practice for them to be used, you will be able to feel that you have provided injections or other painful procedures as humanely as possible.

6.4. INTERVENTION PROCEDURES

There is little inclination on the part of parents or other caregivers to discuss an upcoming painful event such as an immunization injection with a preverbal child. However, as children become increasingly verbal, especially when they begin to anticipate future events and ask "why" questions, parents begin to consider if they should, and how they might, prepare their children for immunization injection pain. Some feel strongly about preparing the child, whereas others think it better not to do so.

Children are most likely to be distressed if prepared too far in advance or not prepared at all (the surprise injection). There is no precise formula for addressing this question. The relative benefits of different timing of informational preparation for injections have rarely, if ever, been studied. Based on clinical observation, it is probably best to tell a preschool-age child about getting a "shot" just a few minutes before it will occur. This will prevent the child from experiencing unnecessarily long intervals of anxiety or anticipatory distress. It will also help him or her not to experience the injection as a random painful event. Such an event can be traumatic and a source of conditioned anxiety. As discussed previously, experiencing distress whenever entering a medical setting, when seeing a health care professional, or when seeing medical equipment and supplies is evidence of conditioned anxiety. Of course, when children directly ask in advance

whether or not they will be receiving an injection, they deserve an answer, and as they begin to ask and anticipate, more conversation will be required. If the caregiver knows there will be an injection, then the child deserves an honest answer. However, a simple "yes" and mention of what might be done to make it less painful (numbing cream, distraction, etc.) are sufficient. Similarly, if the adult is uncertain about whether or not an injection will occur, then honesty is the best policy. The adult can say "I don't know, but if you do need a shot, there are things we can do to make it go a little easier for you" (e.g., numbing cream or distracting activity during the injection, and providing a favorite activity or treat afterward).

Caregivers should avoid being dishonest or euphemistic when answering the child's questions. Statements such as "this won't hurt" or "it's just a little" are dishonest, discount the child's feelings, and sow the seeds for the child to distrust adults, particularly during medical care. The honest answer is that an injection will most likely hurt, but it will be over quickly.

There also is evidence that parental demeanor and behavior can affect the child's behavior during an injection. There is evidence that excessive parental reassurance, criticism, or apology all seem to increase distress, but use of humor and distraction by parents tends to decrease child distress.[4]

A preferred and captivating toy or activity can be an effective distraction that can decrease pain perception. The distraction techniques selected need to be adjusted to the age, temperament, and interests of the child, but overall the efficacy of distraction is well supported by research.[4] While the research supporting distraction will be discussed in greater detail below, some examples of distractions that have been used to decrease immunization discomfort include blowing bubbles and blowing on a pinwheel.[7–8]

Overall, RCTs have supported that among behavioral interventions for needle-related procedural pain and distress in children and adolescents, only distraction, hypnosis, and the combination of the two have been shown to be reliably effective in reducing self-reported pain or distress.[9]

If the physician or nurse is willing to use them, topical anesthetic creams also have been shown to decrease immunization pain or distress.[10–13] Given the evidence supporting their effectiveness, information about the availability of distraction and topical analgesics should be provided in developmentally appropriate language when the child is informed about the impending injection (assuming that these interventions will actually be provided to the child).

Due to the risk for conditioned anxiety that may generalize to other nonpainful medical stimuli, it is important to associate the procedure with

prominent and unique environmental stimuli (a procedure room or location that is only used for such procedures; a specific room color, exam table, or chair; etc.). This may help the child avoid negative associations with doctors visits or medical settings in general. The procedure room can also have unique positive stimuli such as handheld computer games, a portable DVD player, or interactive toys that are only available to the child in that setting. These items or activities can be used for distraction and counterconditioning during procedures, may help to decrease the duration of anticipatory and post-procedure distress, and may decrease pain perception and distress behavior during the actual painful stimulus (needle stick).

6.5. Special Considerations for Children with Intellectual and Developmental Disabilities and/or Severe Behavior Disorders

The special considerations discussed in chapter 5 also apply to children getting immunization injections or similarly painful medical procedures to the extent that they present with severe disabilities or dangerous behavior at this young age. For some children it will be challenging to get them to allow the placement of a topical anesthetic and the covering bandage and to leave it in place once applied. This may require some physical guidance and blocking of disruptive behavior. Also, for very young children with or without intellectual and developmental disabilities, the discomfort associated with removing adhesive tape used to secure the bandage over the anesthetic cream may be as distressing as the injection itself. If this is the case, the same behavioral pain management techniques apply to this stimulation as well. Alternatively, the bandage coving the anesthetic cream could be secured with a Velcro wrap.

6.6. Supporting Literature

Local Anesthetic Approaches

Local anesthetics have been used commonly to block pain perception in skin and subdermal tissue during painful procedures such as surgical incisions, intravenous (IV) line insertion, accessing a surgically implanted IV port through the skin, and stitching up a wound. Local anesthetics used with pediatric patients include medications such as lidocaine, benzocaine, and tetracaine used alone or in combination with epinephrine. However,

these local agents have not been widely adopted for needle stick procedures because they do not always completely eliminate pain, require an additional needle to inject liquids, and may cause local irritation or general toxicity.[14-16]

Until the introduction of an easily melted (eutectic) mixture of local anesthetics (EMLA—Astra Pharmaceutical Products, Inc., Westborough, MA) in the early 1980s,[17-20] lidocaine was intermittently used for simple needle procedures because of its rapid effects and relative safety.[14] EMLA is a topical cream containing the active ingredients lidocaine and prilocaine. These active ingredients are local anesthetics that accumulate around pain receptors in the upper layer of skin and nerve endings. They act to inhibit conduction of nerve impulses. EMLA must be applied to the skin at the site of the needle stick an hour or more in advance to provide local anesthesia. Close supervision is required while a child is wearing EMLA to prevent its ingestion or contact with the eyes.[16] Side effects such as blanching, redness, itchiness, and occasionally blistering of the skin at the application site have been reported.[21-22] Several published papers have reported that EMLA in combination with distraction and coaching is effective in decreasing child behavioral distress during a variety of needle procedures.[15] Over a decade ago, investigators studied a sample of 160 children ages 2–16 who were prepared with EMLA for IV insertion and randomly assigned to either a distraction or a usual care group. The combination of EMLA, distraction (bubbles, electronic storybooks, music via headset), and nurse coaching decreased behavioral distress scores below the level observed with EMLA or usual care alone.[23]

The widespread use of EMLA has been limited by the belief that EMLA causes vein constriction, which may make IV procedures more difficult. Physiological studies[24] have confirmed vein constriction in the first 90 minutes after EMLA application, but after 90 minutes vein expansion[24-26] was observed. One study found that research assistants who were not informed about whether or not EMLA was used made more comments in their observational notes that an IV procedure performed on 5- to 18-year-olds was "difficult" when EMLA rather than placebo was used. On the other hand, medical staff performing the procedures could not accurately differentiate children who had been prepared with EMLA from those prepared with placebo cream.[27] It is also important to recognize that vein constriction from EMLA has not been distinguished from vein constriction associated with patients' clinical symptoms such as fever, dehydration, or pain, which

may have a greater influence on vein diameter and IV success than use of topical anesthetic.[28]

Based on the observation that preschool-age children may be distressed by removing the usual bandage covering the EMLA,[27,29] it is recommended that the EMLA site be covered with plastic wrap and secured with tape that does not touch the skin or by a Velcro cuff for younger or highly anxious children.

The use of EMLA also may be limited by health professionals forgetting to prescribe it, by parents lacking the time or resources to get the prescription filled, or because of the lack of standing orders or product unavailability in the clinic.[30-31] Finally, EMLA is only effective to a depth of 5 mm and does not prevent pain during deeper procedures such as intramuscular injections.[32]

Other less well known options for needle site preparation in school-age children have been reported and shown to have effects comparable to those obtained with EMLA. For example, cooling liquid or spray such as ethyl chloride or fluori-methane applied using a saturated cotton ball 15 seconds before the needle stick is faster and cheaper than EMLA.[33-34] However, recent studies, including an RCT, have indicated that these cooling sprays used alone do not decrease immunization distress in preschoolers.[35-37] The effects of coolant spray with older children having significant anticipatory anxiety due to repeated needle sticks are not known, and its use in combination with behavioral interventions has not been studied.

Another topical anesthetic technique, marketed as "Numby Stuff" (IOMED, Inc., Salt Lake City, UT), uses a pad connected to a drug delivery electrode, which is moistened with 1 cc of iontocaine placed on the skin at the intended needle insertion site. A mild electrical current is delivered for about 10 minutes.[22,38] Topical anesthesia to a 10 mm depth can be accomplished in 10–15 minutes. Children treated with this product have reported less pain during immunizations and IV placement than with EMLA. This is likely because EMLA achieves only 5 mm depth of anesthesia.[32,38] The cost is about the same as for EMLA, but some children have reported having an uncomfortable tingling sensation when using Numby Stuff.[38]

Amethocaine (also known as tetracaine) has been shown to produce greater pain reduction than EMLA and is less likely to produce vein constriction in the skin during a 60-minute application time. In fact, amethocaine has been shown to expand the veins during this time frame.[39-40] Amethocaine is effective in half the time (30 minutes compared with 60

minutes for EMLA),[41] has a longer duration of anesthesia, and has a similar tolerability record compared to EMLA.[16,26,42–44] Furthermore, amethocaine is less expensive[28] and appears to be effective at reducing immunization pain in 1-year-old infants.[41]

Over the past 25 years, as more commercially available options for topical anesthesia have become available, there has been a gradual decrease in the time required for full analgesic effect, and some systems of delivery now require only five minutes or less. The most recent approaches include laser-assisted, ultrasound-assisted, and powder injection anesthetic delivery systems.[45]

Behavioral and Cognitive-Behavioral Management of Acute Pain from Medical Procedures

Behavioral and cognitive-behavioral interventions such as controlled breathing, progressive muscle relaxation, visual imagery, hypnosis, and distraction all have been used to supplement pharmacological management during procedures such as injections,[15,46–48] dental treatment,[49–50] chemotherapy,[51–52] lumbar puncture and bone marrow aspiration,[53–55] and cardiac catheterization.[56] Distraction interventions have used activities such as conversation, toys, cartoons, video games, and virtual reality to divert the child's attention from the painful procedure to decrease pain perception and manage behavioral distress.

If a child has already experienced a painful injection, conditioned anxiety may have developed, and the child may become distressed upon entering the clinic. The previous painful procedure may be consciously remembered and pain anticipated, or the child may experience conditioned anxiety without explicit memory of the past procedure. Children with chronic health conditions requiring repeated painful procedures are at greatest risk for conditioned anxiety. However, for some children even a single painful procedure may lead to conditioned anxiety that can significantly impact future behavior in medical settings.[57]

While research has shown a variety of cognitive-behavioral interventions such as controlled deep breathing, progressive muscle relaxation, visual imagery, and behavioral rehearsal to be effective,[58–60] they are not helpful for infants and very young children because of the cognitive skills required for these techniques.[37] Distraction is more appropriate and effective for these young children because it does not require as much cognitive development to be useful.[51] Several investigators have suggested that dis-

tracting the child's attention from the painful stimulus is a critical component for effective distress reduction in young children.[15,51,61-62]

Distraction-Based Interventions

The mechanism by which distraction reduces pain perception is not fully understood. Some have argued that feeling pain is not a fully automatic process and requires some active attention to and thinking about the painful stimulus in order for it to cause distress. Assuming that a person's attention span is limited, then another stimulus might compete enough with the painful stimulus to alter the degree that the person feels pain.[62-63] Consistent with this theory, recent neuroscience investigations using high-tech brain scans to measure pain-related brain activation have demonstrated reductions in activation of the areas of the brain which process pain when people were engaged in a distracting activity such as completing a maze or other mental tasks.[64-66] Reviews of distraction interventions with children report no compelling consensus on the most effective form of distraction for specific procedures or child ages.[60-67] The distraction techniques that have been successfully employed include music,[46] counting objects in the room,[68] deep-breathing exercises,[7,68] blowing on a party favor,[69-70] nonmedical conversation,[69] toys, puppets, books, bubbles,[69] videotaped cartoons,[71] movies,[15,72] video games,[73] electronic "smart" toys,[74] or a choice of several distracting activities.[75] Many of these techniques have been used in conjunction with parental prompts and/or some sort of positive reinforcement for cooperation or for using the distracting activity.[51] Parental coaching may increase the child's use of a distracting activity, but under some circumstances it may increase rather than decrease child distress in some younger (3- to 4-year-old) children.[76-77] Nurses also have been trained as coaches, and there is evidence that the combination of movie distraction and nurse coaching can significantly increase child coping and decrease child distress during painful medical procedures.[15,72]

Interactive Distraction Interventions

It has been hypothesized that an activity requiring an optimal (but not overly taxing) amount of attention would compete to a greater degree with a painful stimulus for a child's limited attention and perceptual capacity than a simple distractor.[61] Thus, a distractor that requires using a number of different senses (i.e., vision, hearing, touch), that requires the child to

actively participate rather than passively watch, and that requires some mental activity should be maximally engaging and therefore maximally distracting.

Video Games

Video games during chemotherapy have decreased self-reported and observed distress before and during chemotherapy, as well as decreasing aversive side effects such as nausea. Compared to baseline without video games, the availability of these games in one study reliably reduced the number of anticipatory symptoms both reported by the patients and observed by the investigators, as well as the severity of self-reported chemotherapy side effects.[73]

Electronic "Smart" Toys

Some investigators[58] have tested a distraction intervention that could be varied along several dimensions and required an active behavioral response (e.g., push a button, name a color). An electronic toy with several picture panels that could be interchanged to match the child's interests and ability was used. The toy played the voice of Mickey Mouse telling the child to press a picture on the panel. Pressing a picture produced an accompanying sound. Thirty-nine children with cancer between the ages of 2 and 5 were observed during three or six pre-distraction intramuscular injections during which chemotherapy was administered. Then the children were provided the distracting activity during three subsequent chemotherapy administrations. Results indicated a significant reduction in behavioral distress during the distraction condition, with 69% of the children showing at least a 20% reduction in behavioral distress. Improvements were maintained over three intervention sessions spanning approximately eight weeks.[58]

A related study[74] examined the effects of a similar distraction intervention provided to children undergoing repeated injections. Eight preschool-age children and their parents were trained to play with an interactive electronic toy robot during chemotherapy or transfusion injections. Initially, the therapist was present during the procedures and prompted the child to play with the toy. Over subsequent procedures, the parent gradually learned to prompt and praise the child for playing with the toy, and the therapist's prompting was gradually faded out. This intervention re-

duced overt behavioral distress in five of the eight children. Of those who improved, three were able to maintain the reductions in behavioral distress over 3 to 16 weeks.[74]

Virtual Reality

Virtual reality computer games employ three-dimensional computer-generated video displays that are interactive and provide vision, hearing, and movement stimulation. This combination seems to provide the ideal medium for distraction during painful procedures. This intervention has been investigated with children undergoing dental treatment,[78] burn-wound care,[79] and IV tube placement.[80] However, expense, availability, and the need for special computer equipment limit the use of virtual reality for routine procedural pain intervention during immunization injections.

It should be noted that to be effective, distraction must substantially compete with the child's attention to stressful medical stimuli. The potential of a stimulus to distract depends on how captivating and fresh it is for the child. Videotapes can be captivating, and their variety ensures that something new is relatively easy to find. In addition to being captivating and fresh, video games, electronic toys, and virtual reality also prompt interaction from the child. To be most effective, distraction probably should include salience, variety, and automatic prompts for physical responding (e.g., pressing buttons, touching or moving objects) while also being inexpensive, portable, and appropriately structured for the child's level of development.[58]

Younger children tend to exhibit greater observable distress and seem to benefit most from behavioral interventions that teach them to perform coping behaviors that are compatible with their developmental tendency to employ primary control coping strategies (behavioral attempts to alter the immediate environment). Recent studies employing interactive distraction with computer games, "smart" electronic toys, and virtual reality suggest that these interventions may be cost-effective and are well suited for and effective with young children. As discussed above, distraction techniques have been studied extensively and are well established as an empirically supported intervention for preschool- and school-age children.[58–59] Recent studies have documented the benefits of distraction in reducing behavioral distress in 1-month-old to 3-year-old children during immunizations.[37,81] These studies employed movie distraction with very young children. The distraction involved presenting

the child with a program such as *Sesame Street* or *Teletubbies* played on a portable video player. The interventions also involved brief parent training on how to redirect their child's attention to the video display. The positive benefits were observed primarily during anticipation of and recovery from the needle stick; not surprisingly, these interventions did not decrease distress during the moment when the needle was inserted.

Finally, a recent innovative study employed a multifaceted distraction-based intervention to decrease pain during immunizations of 4- to 6-year-old children.[82] In this intervention, verbal suggestions of decreased sensation and a visual and tactile focusing activity were combined with a cooling spray (topical ethyl chloride). The focusing activity used an improvised, plastic, multipronged arm gripper and a vibrating instrument descending on the arm opposite from the arm selected for the injection. Based on patient and parent ratings and direct observation data coded from videotapes of the procedures, the children receiving this intervention showed highly significant reductions in pain and discomfort compared to an office routine control group. These encouraging results have led to variations on the multifaceted distraction approach that is currently being tested clinically. This creative intervention includes a plastic bee named "Buzzy" that has frozen wings and vibrates and is attached with a Velcro strap over the tourniquet for IV insertions or held by hand just above the insertion site for injections. In all cases it is combined with distraction cards prompting modest cognitive tasks such as counting stars. This intervention package is commercially available (www.buzzy4shots.com) and is being field tested. While this particular combination has not yet been empirically validated with an RCT, it is based on the same theoretical conceptualization as the previous study by the same investigators.[82]

It is inevitable that additional research will be conducted on this type of multifaceted distraction intervention with preschool-age children undergoing immunization injections. At this time, the literature indicates some empirical support for the combination of techniques listed below as an effective intervention for needle stick pain and distress in preschool- and school-age children.

EMPIRICALLY SUPPORTED TECHNIQUES

1. Prepare the needle insertion site with a topical anesthetic (EMLA or amethocaine), and do so far enough in advance to ensure that it has time to be effective.

2. Provide sensory distraction using brief application of cold stimulation (e.g., small ice pack) to a different area of skin (opposite arm or same arm above needle site) when injection is given.
3. Provide other developmentally appropriate multisensory stimulation (distracting touch or vibration).
4. Provide an interactive distraction activity requiring modest amounts of attention, mental effort, and physical manipulation (blowing bubbles, playing with electronic push-button books or toys).
5. Provide calm, neutral-toned verbal prompts at low conversational volume to remind the child to look at and play with the toy.
6. Provide calm, low-volume praise for any cooperation and for playing with the toy.

With regard to other evidence-based interventions that are effective for reducing child pain and distress during immunizations, two recent studies conducted meta-analyses after systematically reviewing the literature for RCTs. One study included 23 RCTs involving the use of pharmacologic and combined interventions in their meta-analysis. The results indicated that topical anesthetics, sweet-tasting solutions, and combined analgesic interventions, including breastfeeding before, during, and after the injection, were associated with reduced pain during immunization injections and are recommended for clinical practice with infants.[83]

The second study included 20 RCTs of various psychological interventions for reducing pain and distress during immunizations. The results of the meta-analyses documented significant empirical support for using breathing exercises, child-directed distraction, nurse-led distraction, and combined cognitive-behavioral interventions for reducing immunization pain and distress.[84]

Continued research using RCTs is needed and encouraged in this field, but as this chapter suggests, there are many promising behavioral and cognitive-behavioral strategies that appear to be helpful for reducing immunization pain and distress. Matching interventions to children with different ages, temperaments, and learning and medical histories is an important part of clinical practice and individualization of care. The various types of interventions discussed in this chapter make up the current

"toolbox" from which parents and health care professionals may choose when developing an individualized pain and distress management plan for young patients undergoing immunizations.

KEY CONCEPTS

- Pediatric pain research has shown that infants experience pain much like adults and possibly with greater intensity.
- For some children even a single painful procedure may lead to conditioned anxiety that can significantly impact future behavior in medical settings.
- Children are most likely to be distressed if prepared too far in advance or not prepared at all for injection pain.
- Statements such as "this won't hurt" are dishonest, discount the child's feelings, and sow the seeds for the child to distrust adults during medical care.
- Pharmacological, behavioral, and cognitive-behavioral interventions are available to decrease anxiety, pain, and behavioral distress; increase coping; and decrease recovery time for immunizations.
- If physicians or nurses are willing to use them, topical anesthetic creams such as EMLA and amethocaine have been shown to decrease some children's immunization pain or distress.
- Distracting the child's attention from the painful stimulus is a critical component for effective distress reduction in young children.
- A preferred and captivating toy or activity can be an effective distraction that can decrease pain perception.
- Distracting activities should be used in conjunction with care provider's prompts to use them and positive reinforcement for cooperation and participation.
- Matching specific interventions to specific children according to their ages, developmental levels, temperaments, and learning histories (both behavioral and medical) is an essential part of managing childhood immunization pain and distress.
- It is important to associate the procedure with prominent and unique environmental stimuli (a procedure room or location

only used for such procedures; a specific room color, exam table, or chair; etc.). This may help the child avoid conditioned negative associations with doctors visits or medical settings in general.

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Cooperation and Motion Control for Diagnostic Tests and Treatments

IN THIS CHAPTER

- This chapter discusses how children with chronic health conditions often require medical diagnostic tests for which they must cooperate and hold still.
- Task analysis methods are reviewed and discussed with regard to how they can be used for both teaching and measuring the behavior required for a child to cooperate and hold still for medical tests and treatments.
- The chapter elaborates on behavioral principles and strategies used to teach general child compliance and how they can be applied to teaching cooperation and control of movement during medical procedures.
- Illustrative examples from the author's clinical experience and research are presented.
- Some ways in which behavior analysis procedures can be used to avoid sedation for medical tests are highlighted.

7.1. PATIENT POPULATION AND TARGET PROBLEM(S)

Diagnostic tests such as X-rays, computerized tomography (CT) scans, magnetic resonance imaging (MRI) scans, electroencephalograms (EEGs), polysomnography (PSG), and sonograms (ultrasound) require the child to assume a specified physical position and to hold still for the duration of the procedure. Although these tests are not common in the lives of most typically developing children, those with chronic health conditions often experience them repeatedly.

The medical procedures discussed in this chapter are not painful, and given appropriate introduction and training, most children can learn to cooperate with them. Medical procedures are difficult for children because they are exposed to unusual physical sensations (sights, sounds, smells, positions, touch with sensors, etc.), and because the child cannot move freely. As discussed earlier in this book, these characteristics of the medical situation may be experienced by the child as nonpreferred or aversive, and the child may become distressed and attempt to avoid or escape them. Therefore, the primary objectives of behavioral intervention to prepare children for nonpainful diagnostic procedures are (1) to provide information to the child about the sensations she or he will experience and the behavior that will be required during the test; (2) to use real or simulated equipment to gradually expose the child to these sensations and behavioral demands; (3) to teach the child to cooperate by following instructions, getting into and remaining in position, and inhibiting movement that would distort the test results; and (4) to provide and teach the child to use a distracting activity to help cope with any aversive aspects of the procedure.

The techniques presented in this chapter are applicable to children with or without intellectual and developmental disabilities (IDD) having any type of health problem requiring technological diagnostic testing or treatments. The training protocols described here are most important for preschool-age children (ages 3–5) and early-school-age children (ages 6–9). Although by age 9 most children will not need special training for diagnostic tests, children and youth with IDD or those with neuromotor disorders, anxiety disorders, or attention deficit hyperactivity disorder (ADHD) may continue to benefit from these behavioral interventions at older ages.

7.2. ASSESSMENT PROCEDURES

The concept of task analysis was introduced briefly in chapter 2. To review, it refers to breaking a complex behavior or task into component steps and then prompting the child to perform them, one step at a time, documenting his or her success at each point. These data are recorded during each session to document behavior change as a result of training or other behavioral intervention. By carefully noting the child's performance and behavioral reactions at each step in the task analysis, it is possible to determine where more (or different) training is required to achieve progress and, ultimately, success. As will be shown later in this chapter, it is helpful

to track the child's performance across training sessions in graphic format to evaluate progress over time.

In preparing a child for any type of medical procedure, it is critical to evaluate the degree to which the child is under the instructional control of the caregiver (parent, medical staff, or behavior therapist). If the child does not follow caregiver instructions for basic behavioral demands (e.g., "come here," "sit down," "hold my hand," "use a quiet voice"), then he or she is unlikely to cooperate with more challenging demands for positioning and motion control in the context of a nonpreferred medical activity. Therefore, initial behavioral intervention may need to include an emphasis on basic compliance training.

7.3. INTERVENTION PROCEDURES

Compliance Training

Compliance training has been studied experimentally by behavior analysts,[1] and this research describes a general set of procedures for training children to comply with caregiver instructions. First, several examples of common caregiver instructions are selected, such as those mentioned above. Next, preferred stimuli for the child are identified in order to be used for positive reinforcement. Finally, the list of demands is presented periodically during the day, and compliance with instructions is differentially reinforced while noncompliance is placed on extinction (not reinforced). In this situation, extinction involves both withholding positive reinforcement if the child does not comply within 10 seconds and not allowing the child to avoid or escape from the demand due to inappropriate behavior such as running away, hiding, hitting, or having a tantrum. To prevent escape, it may be necessary for the caregiver to continue prompting the child to complete the instructed behavior. Prompting begins with a specific verbal instruction ("sit down"); then, if necessary, the same verbal prompt is paired with a gesture, a demonstration (caregiver modeling), or ultimately physical guidance. In most cases, if this set of procedures is practiced regularly, the child will show striking improvement in compliance with generalization to instructions that have not been specifically trained (stimulus generalization). Children may be trained to follow "do commands," which state specifically what the child is to do, or "don't commands."[2] Don't commands do not teach the child about specific behavior to engage in that will result in positive reinforcement. That is,

once a child has followed a "don't command" and stopped a problem behavior, he or she must decide what other behavior to perform. However, without specific instruction as to what to do, the child may simply move from one problem behavior to another.

Following the above line of reasoning, when children who are observed to be under poor instructional control require a medical procedure, behavioral training should begin with simple instructions with which the child is most likely to comply in order to establish a history of positive reinforcement for instruction following. Basic compliance training as described above may be needed. However, most children will comply with a play-related activity, so beginning a training session with such an activity may be an adequate situation to begin reinforcing compliance with caregiver instructions. Over time, both within and across sessions, the difficulty of the behavioral demands placed on the child can be gradually increased and reinforced as tolerated. Once the child is consistently compliant with the compliance training demands, they can be gradually integrated with the beginning steps of the task analysis for the mock medical procedure.

Gradual Exposure for Desensitization to the Medical Equipment and Routine

As the child is presented with the steps in the task analysis involved in the simulated medical procedure, gradual exposure to sensations and the required behavioral routine is accomplished. Successful cooperation is reinforced at each step or after designated time intervals of cooperation. This exposure proceeds systematically with gradually increasing demands for cooperation and behavioral performance, as long as the child continues to achieve success. At the point at which the child is no longer able to cooperate, demands are reduced slightly until success occurs, and then the training session can be ended with both positive reinforcement (praise, prize, preferred activity) and negative reinforcement (termination of the task) for successful cooperation. Subsequent sessions may then require additional skill training or greater incentives to continue progression through the entire task analysis.

Exposure to nonpreferred stimulation and challenging behavioral demands can be facilitated by adding other forms of stimulation that *are* preferred and provide positive motivation and distraction for the child. That is, if some aspect of the procedure can include a game, fun activity, and/or reward for cooperation and approximations of success, the child will be

more motivated to approach and interact positively with the medical staff and equipment. This can be accomplished by including, whenever possible, "child-friendly" activities such as entertainment with music, audiovisual presentations (e.g., DVD movies), books, and games. The types of preferred activities that can serve as both distraction and continuous reinforcement were described in chapter 6 when discussing interactive distraction strategies. Such activities may be used in training programs for specific types of medical procedures. If a child can be involved in a preferred game or earn points toward a prize at the end of the procedure, his or her motivation to cooperate with both simulated and real medical procedures is likely to be enhanced.

Differential reinforcement was introduced in chapter 2 as systematically providing preferred items or events in response to those behaviors to be increased in frequency (e.g., compliance, cooperation, low rates of movement), but not in response to those one intends to decrease (e.g., avoidance, escape, disrupting medical equipment). Differential reinforcement is a critical component of behavioral interventions to obtain child cooperation and motion control during medical procedures. Use of differential reinforcement by therapists, parents, and medical caregivers can foster an interaction style in which children are encouraged and rewarded for what they do right and given minimal, if any, attention for what they do wrong. Caregiver effort is focused on acknowledging and rewarding the child's successes and improvements, no matter how small, rather than emphasizing failure or deficits.

To emphasize points made in chapter 2, it is important to remember that there is always the possibility of inadvertently reinforcing problem behavior with social attention. Both positive social attention (asking what is the matter, attempting to soothe) and negative social attention (verbal reprimand) can reinforce problem behavior. Similarly, if undesirable behavior occurs in response to task demands and the caregiver discontinues the demand, this may negatively reinforce the problem behavior (the child is able to escape a nonpreferred demand or situation).

Neuroimaging

Over the past two decades, MRI has become a routine diagnostic medical procedure employed with patients of all ages and especially those with chronic health conditions requiring long-term monitoring. MRI is used routinely with children, and MRI of the brain is very common for children

with congenital or acquired neurological abnormalities. MRI has no known risks, except when uncooperative patients require sedation, and when an injected contrast agent is required for special types of imaging. Sedation and contrast increase the risk of adverse effects for patients with certain types of allergies and cardiac or pulmonary conditions.

MRI is noninvasive, but the patient must lie in an enclosed, noisy machine for 20 minutes or more. Movement decreases image quality. Some very small, infrequent movements can be compensated for by the scanner's computer software, but in general, movement degrades the images or makes them unreadable. Sedation is ordered to prevent movement in many pediatric cases, especially for children under age 7. Sedation adds the risk of undesirable side effects such as temporary hypoxia, respiratory depression, vomiting, persistent altered consciousness, and sleep disturbance.[3] The author of this book has been a pioneer in the area of behavioral training for children requiring MRI of the central nervous system.[4–6]

Advances in radiotherapy techniques have made this type of treatment for malignancies more precise than ever. With the use of imaging techniques such as MRI and CT for guidance and planning and the use of lasers for aiming the radiation, it is increasingly possible to eradicate malignancies while minimizing radiation damage to adjacent normal tissues. However, to achieve this goal, the patient must remain in a fixed and reproducible position for each radiation treatment. Radiation therapy is typically conducted daily for up to six weeks and as many as 35 treatments.[7] Movement or position change of the targeted body part during radiation treatment can cause unplanned irradiation of normal tissue with significant impact on treatment outcome.[8–9] While the radiation treatment itself is not felt by the patient, children often experience fears and anxieties caused by meeting strangers, separation from parents, and exposure to the unfamiliar sights and sounds of the radiation equipment. Furthermore, due to conditioned associations between medical stimuli and previous painful medical procedures (e.g., bone marrow aspiration, lumbar puncture, venipuncture, IV insertion), they may be afraid and uncooperative whenever they encounter new medical situations, equipment, and procedures.

With occasional exceptions, children 30 months of age or younger require daily sedation or anesthesia to guarantee cooperation and immobility during radiation treatment. Children between 30 months and 12 years of age also may require repeated sedation or anesthesia unless they can be taught to lie still for the time required for radiation planning and position-

ing (referred to as "simulation") and daily treatments.[7,10] Some older children with severe anxiety reactions, a history of behavior problems, and/or developmental disabilities also have difficulty cooperating and may require sedation or anesthesia for radiation therapy.

Children who are emotionally aroused, particularly those with developmental disabilities and other neurological impairments, can be difficult to sedate and may respond unpredictably to the pharmacological agents used.[11–12] Depending on the agent employed, up to 20% of these children cannot be effectively sedated and therefore require anesthesia to receive their daily radiation treatments.[7] Unfortunately, use of repeated, high doses or multiple sedatives or use of general anesthesia increases the risks of complications such as vomiting, significant drop in blood oxygen saturation, and apnea.[7,13] Drug administration and increased patient monitoring involved in sedation and anesthesia also add expense to already-expensive radiation treatment protocols. Considering the increased risks and costs associated with sedation and anesthesia, it is preferable to avoid these approaches to motion control, if possible.

A number of intervention strategies, including some demonstrated by the author of this book, have been described as helpful in preparing children for radiation therapy.[7,14–19] First, it is recommended that information about the procedure be provided in a format that the child can comprehend. This involves brief verbal explanations, demonstrations with dolls or puppets[14] or in vivo modeling (watching a parent or another child go through a mock procedure), and role playing by practicing lying still in a nonthreatening environment. Emphasis is placed on explaining the routine and sensations involved in radiation treatment using developmentally appropriate words, pictures, and demonstrations. Distraction and reassurance may be provided by having a radiation oncology staff member, child life specialist, behavior therapist, or parent talk, read a story, and give praise through an intercom in the radiation therapy room. Behavior required for successful treatment should be explained using simple and clearly stated rules. Cooperation should be taught by differential reinforcement using praise, simple tangible rewards, or treats.

It should be made explicit that there are circumstances under which this approach is not appropriate or feasible. For example, when retinoblastoma is being treated, no eye movement can be tolerated; thus, paralysis of the extraocular muscles is required to protect vital tissues of the eyes.[7] However, in many other cases a behavioral approach can be justified and

can successfully enable the child to cooperate and avoid the risks and inconveniences involved in daily sedation or anesthesia. Even when children are not able to cooperate with the more extended interval of cooperation and lying still required for radiation therapy planning ("simulation") lasting up to 90 minutes, with behavioral training, they may still be able to receive their treatments without sedation or anesthesia because the treatments require much shorter intervals of immobilization (e.g., 15–30 minutes).

The author and colleagues[17] developed and demonstrated the utility of an approach to training children to cooperate with radiation therapy based on the principles of learning and behavior employed within the field of applied behavior analysis. They used behavioral training techniques to desensitize preschoolers and children with special needs to the radiation treatment protocol and to learn motion control in order to cooperate with therapy. A detailed description of their behavioral program is presented in the text that follows. It involves three parts: (1) desensitizing the anxious or frightened child to the radiation equipment, staff, and routines; (2) motivating the child to cooperate with staff instructions during treatment; and (3) teaching the child to hold still for the necessary period of time.

Desensitization and exposure therapy are behavior therapy techniques used for treating anxiety, fears, and phobias. Exposure therapy involves relaxing the patient using techniques such as deep breathing, progressive muscle relaxation, or visual imagery. In young children this can be accomplished by providing them with comforting things such as music, cartoons, or stories and then gradually introducing the feared object or situation using visual imagery or live exposure. This systematic pairing of comforting and feared items is conducted using a series of increasingly challenging exposures until the patient can comfortably approach the previously feared object or situation.

Many aspects of radiation treatment can be frightening to a young child. The child requires desensitization to the equipment, staff, and routines before attempting to position the child and begin radiation treatments. This involves scheduling a time for a rehearsal, during which the child visits the radiation therapy suite without the usual time pressure involved with treatment. The child can be exposed gradually to the radiation therapy suite and equipment at a pace that challenges the child with new experiences but does not cause overwhelming distress that would interfere with learning. This allows the child to learn to trust the medical staff and to gain

TABLE 7.1 Radiation Treatment Desensitization Hierarchy

1. The child is instructed to look at an array of small toys and prizes displayed in or near the treatment or simulation area.
2. The child is instructed to select a prize to be earned for cooperative behavior and stickers to be awarded for performing specific tasks.
3. The child is instructed to perform a simple task such as sit on a designated chair or take a brief walk with a staff member to earn a sticker.
4. The child is instructed to sit on the patient support of the equipment to have a picture taken and earn a sticker.
5. The child is instructed to lie down on the patient support to have another picture taken and earn a sticker.
6. The child is instructed to lie in the required position and hold still for a count of 10; another picture is taken and a sticker earned.
7. The child is instructed to lie in the required position while the beam generator is positioned and then the technologist counts to 10; "a picture" is taken with the "special camera" (referring to but not actually activating the beam generator) and a sticker is earned.

Source: Slifer, K.J., Bucholtz, J., & Cataldo, M.D. (1994). Behavioral training of motion control in young children undergoing radiation treatment without sedation. *Journal of Pediatric Oncology Nursing*, *11* (2), 55–63. Reprinted with permission from Sage Science Press.

confidence in his or her own ability to cope during the future radiation therapy procedures. The child learns by experience that nothing painful will occur in this setting. For this reason it is recommended that any painful procedures required for treating the child's malignancy or monitoring his or her health status be conducted elsewhere and separated from the radiation treatments by time, distance, and use of different staff.

As the exposure therapy and desensitization progress, a planned desensitization hierarchy is followed. In the hierarchy employed by the author and colleagues,[17] the child is first instructed to perform a simple task (see table 7.1). For example, the child is prompted to sit on a parent's or caregiver's lap to have a photograph taken, or to enter an empty exam room and select a toy. Cooperation and instruction following by the child are positively reinforced with praise and age-appropriate toys or other small rewards. Through this process of combined exposure and compliance training the child learns that compliance with staff instructions results in positive events in this setting.

After the child demonstrates success at following easy instructions, the behavioral demands of the practice session are gradually increased, requiring more challenging actions such as sitting on or near the equipment or temporarily leaving the parent's side. The child is provided positive

reinforcement for performing progressively more difficult tasks. With proper pacing and carefully selected reinforcers, children can learn to approach settings and equipment that otherwise would have frightened them.

To successfully motivate child cooperation, radiation oncology staff should arrange for events preferred by the child to occur as a consequence of acceptable cooperation. Such reinforcing events include receiving praise, tokens, stickers, toys, treats, or access to special activities. It is critical to remember that the same reinforcer does not work for every child. Different children have different preferences, and any given child may have different preferences from day to day. In order to increase the probability of successfully motivating the child to cooperate, three different types of reinforcers can used: (1) social reinforcers such as praise, positive descriptions of the child's appropriate behavior, and verbal and physical expressions of affection (hugs, pat on the back); (2) tokens such as points, coins, stars, or stickers which are delivered contingent on cooperative behavior; and (3) tangible rewards such as toys, trinkets, snacks, preferred objects, or activities which can be "bought" with the tokens after treatments. Once acquainted with the reinforcement routine, the child learns to anticipate the reinforcers associated with treatment.

The reinforcement routine described by the author and colleagues[17] involves showing the child a selection of tangible reinforcers that are displayed on or near the radiation therapy equipment and prompting the child to pick an item or activity she or he wishes to earn for following instructions during treatment. For younger children and those with a limited attention span or difficulty waiting, praise and tokens are necessary to "bridge the delay" until the end of the session. The child can be provided with a sticker chart or cup for collecting tokens and told how many are needed to get the reward that he or she picked at the beginning of the session. Stickers or tokens are paired with praise and awarded for compliance with the steps involved in the radiation therapy task analysis (table 7.1). Following the exposure plan described above, the behavior required for reinforcement can be increased until the child demonstrates all the behavior necessary for successful radiation treatment. This involves (1) entering the treatment area, (2) lying on the patient support of the machine in either a face-down position in a head and body mold (Alpha Cradle) or a face-up position with an Aquaplast mask secured snuggly over face and head,[10] (3) cooperating with alignment checks, and (4) being left alone in the treatment room with the door shut during radiation beam exposure.

Praise and stickers are awarded at naturally occurring intervals in the radiation protocol (after an X-ray or CT image is acquired, after alignment, after placing landmarks, after each dose has been administered, and at the end of the session).

After the first training session or two when the child is no longer very fearful, teaching motion control is the primary focus of training. This requires differential reinforcement of behavior that is consistent with the goal of therapy. Motion control can be taught by differentially reinforcing increasingly lower rates of movement and then having the child lie still for increasing periods of time.[17] A teaching metaphor, having one's picture taken, can be used to explain motion control. Even very young children typically have learned to hold still while being photographed. Using a digital camera to provide immediate feedback, the child can be prompted to hold still and then photographed. In coordination with gradual exposure to the radiation setting and routine, the child can be photographed in the waiting area, hallway, just inside the treatment room, sitting with mother on the exam table, sitting without mother on the exam table, and so forth. Instruction following is reinforced as described above. At first, some movement is tolerated while providing verbal feedback to the child (e.g., "Whoops, you moved your head, please hold very still so the picture will not be blurry"). The child should be prompted to lie down and remain motionless on the equipment while additional photos are taken. The amount of time required for a photo can be gradually increased by counting aloud more and more slowly from 1 to 10. Once the child can reliably lie in position and hold still for a photograph after a slow count to 10, the transition to the radiation equipment can be explained as using a larger camera. This idea can be strengthened by showing the child an example X-ray or CT image as the "picture" that results from using "the big camera." More practice trials are conducted in which the adults leave the room but observe using a video monitor, and both instructions and praise are given to the child using the radiation room intercom. If the child can remain still during these trials, and the interval during which the child remains in position gradually increases to 20 minutes, then actual radiation simulation and treatment can commence.

A critical component of training is that the child's tolerance of longer intervals of motion control can be greatly enhanced by providing distraction and continuous positive reinforcement with an audiotape of music or stories or providing entertainment using a small video display that is compatible with the radiation equipment and positioning.

The Integrated Program

All the components described above can be conducted together by a behavioral psychologist or behavior therapist experienced in teaching children new skills and managing fearful or disruptive behavior. The psychologist or therapist works with the child and consults with the staff during the first one to three sessions. The behavior management routine can then be transferred to the radiation oncology staff and caregiver. As the staff becomes more skilled at behavioral training, the number of patients who require sedation, general anesthesia, or direct services from a psychologist or behavior analyst can be decreased. The benefits of this nonpharmacological approach to child management for radiation therapy have been recognized by some radiation oncologists, but this type of approach may require increased time and effort initially, which makes radiation therapy staff reluctant to adopt it more universally.[10] Of course, there are always specific cases and situations in which behavioral training is not appropriate. Ultimately, the benefits and risks associated with using behavioral training versus sedation or general anesthesia have to be considered by the treating radiation oncologist. However, there does seem to be encouraging evidence that in many pediatric cases behavioral preparation and training can be effective for facilitating child comfort, cooperation, and movement control during radiation therapy.

Electroencephalogram and Polysomnography (Sleep Studies)

The author and his colleagues have developed behavioral interventions to increase compliance with EEG and sleep study procedures in children with or without developmental disabilities.[20] The EEG is a neurophysiological technique used to detect and record electrical activity in the brain. It is used in the diagnosis and management of seizure disorders, such as epilepsy and other neurological conditions.[21] During an EEG, 20 or more electrodes are placed on the child's scalp, forehead, and upper face. A standard EEG is typically carried out during the day and requires placement of the electrodes on the child's head and tolerance of these sensors for about one hour. The child must cooperate with skin preparation (scrubbing with a Q-tip) and placement of the electrodes with adhesive paste and remain still during the recording. Typically the child's head is wrapped in gauze in a turban-like

fashion to keep the electrodes in place. With caregiver support and assistance, the child must also comply with the EEG technologist's instructions.

Some children require continuous EEG recording overnight to evaluate for seizure activity during sleep, which can increase the probability of abnormal brain electrical activity and seizures especially during the transition from sleep to wakefulness.[22] Overnight EEG monitoring requires a child to tolerate placement of the leads, limit physical movement, and keep the electrodes in place until he or she falls asleep and throughout the night. Another type of overnight sleep study is PSG, which is a specialized physiological test conducted to evaluate brain, heart, and lung functions during sleep. PSG is used to evaluate breathing problems during sleep, such as obstructive sleep apnea, and to detect abnormal sleep-wake patterns (circadian rhythm disorders), inability to fall asleep or remain asleep (insomnia), and abnormal behaviors during sleep (sleep walking, night terrors, restless legs). From the perspective of behavioral training for compliance with the procedures, the two types of sleep studies are quite similar, differing only in terms of the types of sensors employed and their exact physical placement. The behavioral protocol discussed below with respect to EEG sleep studies also has been used successfully in training cooperation with polysomnography.[23-24]

Any EEG examination can induce distress in young children and individuals with developmental disabilities because of anxiety about unfamiliar equipment and difficulty inhibiting movement. Children with developmental disabilities also often have tactile defensiveness, which is a pattern of observable distress and avoidance behavior that is out of proportion compared to the response of most people to the same tactile stimulation.[25-27] Without behavioral training, children with tactile defensiveness typically do not tolerate the physical touch involved in placement of the EEG sensors on the scalp and face.

In many settings, children who are uncooperative, have difficulty inhibiting movement, and are distressed by tactile stimulation are managed using a papoose board restraint, sedation, or anesthesia. However, these solutions can alter the test results. Sedation may cause atypical behavior in children with neurological abnormalities, may be ineffective, and may produce problematic side effects such as vomiting or prolonged periods of altered consciousness.[28-29]

In one recent study, sedation with clonidine was suggested to be a safer method of sedation for children with autism, yet 15% of the children were not successfully sedated, and even when sedation was successful, the

clonidine required an hour to be effective.[12] An hour of waiting for sedation to take effect can be quite challenging for the child, caregiver, and health care personnel.

The ability to complete an EEG allows these children to receive neurological care so that their symptoms may be diagnosed and monitored without the discomfort and risks of sedation or restraint. It is often assumed that children with autism and/or intellectual and developmental disorders will be uncooperative for a procedure such as an EEG or sleep study. However, given sufficient opportunity for behavioral training, most children, even those with a wide range of cognitive deficits, emotional problems, and disruptive behaviors, can be trained to cooperate with these procedures.

The behavioral training procedures employed by the author and colleagues[20] are presented below. The training is conducted in sessions of 30–60 minutes in duration. A task analysis based on the detailed sequence of behavioral steps required for successful cooperation with an EEG is outlined in table 7.2. The task analysis is used to measure the percentage of steps completed/tolerated and the percentage of steps attempted during which escape/avoidance or other problem behavior is observed. This is one method of tracking patient progress within and across training sessions.

Good candidates for this training are children with a history of a prior failed attempt at an EEG procedure or who have been anxious and disruptive during other medical procedures that also required similar cooperation, physical touch, and restricted movement. These are children who become noticeably distressed and attempt to avoid or escape medical settings and health care staff.

The behavior therapist should begin by conducting a thorough clinical interview about the child's past behavior in medical and other stressful situations, as well as the child's preferred activities or objects that might be used for positive reinforcement to strengthen the child's motivation to cooperate with the EEG examination. Preferred activities (watching a cartoon) or objects (toys) are used for distraction, counterconditioning, and motivation. Familiar and preferred objects (e.g., stuffed animal or pillow) may be incorporated into the EEG environment to help the child feel more comfortable during the procedure.

During behavioral training, the child is gradually exposed to the materials and sensations involved in scalp and skin preparation and EEG sensor attachment using mock or actual EEG leads. The child is given in-

TABLE 7.2 Task Analysis of EEG Procedures for Behavioral Training

Step	Compliance? Yes/No	Escape/Avoidance Behavior? Yes/No
Enter room		
Get onto bed/chair		
Touch head		
Q-tip on head		
Q-tip with skin prepping gel on head		
Place first lead		
Touch head		
Q-tip on head		
Q-tip with skin prepping gel on head		
Place second lead		
Touch head		
Q-tip on head		
Q-tip with skin prepping gel on head		
Place third lead		
Touch head		
Q-tip on head		
Q-tip with skin prepping gel on head		
Place fourth lead		
. . . . . Continue this same sequence until all leads are attached.		
If all leads were placed, record total time leads were left on _____		
Note. This is a representation. Typical EEG task analyses include placement of 16–25 leads.		

Source: Slifer, K.J., Avis, K., & Frutchey, R. (2008). Behavioral intervention to increase compliance with electroencephalogram (EEG) procedures in children with developmental disabilities. *Epilepsy and Behavior*, *13*, 189–195. Reprinted with permission from Academic Press.

structions one step at a time to enter the therapy room, sit on a bed or reclining chair, lie back in a supine position, and remain still while the therapist touches the child's head with a fingertip, rubs the attachment site with abrasive paste and a Q-tip swab, and then attaches the EEG sensors one by one.

A routine is developed and conducted at the beginning of each session in which the child enters the room and picks a favorite type of sticker or token for use as conditioned reinforcers to be exchanged at the end of the session for a tangible reinforcer (preferred object or activity). Then, the therapist begins the initial steps of the task analysis. During behavioral training, the therapist provides differential positive reinforcement for cooperation, instruction following, and tolerance of the application of the EEG leads. Music, stories, videotaped cartoons, or other favorite activities are provided as continuous positive reinforcement as long as the child is cooperating with the EEG routine. These activities are briefly withdrawn to provide contingent feedback and brief time-out from positive reinforcement for behavior that would disrupt the acquisition of EEG data. For example, the child's favorite video can be turned off briefly after each attempt by the child to remove an EEG lead. The therapist ignores negative vocalizations during the session and praises the child for remaining calm and for observed appropriate behavior.

Negative reinforcement was introduced and defined in chapter 2, but to review here, it involves removing an aversive or nonpreferred item or activity contingent on a behavior, which results in strengthening or increasing the future probability of that behavior. Some disruptive behavior during attempted medical procedure is maintained by negative reinforcement. Therefore, escape extinction is used to eliminate this type of negative reinforcement. When implementing escape extinction, the therapist blocks the patient's escape from a nonpreferred stimulus. Over time, this weakens escape behavior that has been maintained by negative reinforcement. In the protocol,[20] escape extinction is used to teach the child that his or her attempts to remove the EEG equipment will not be successful in producing negative reinforcement via escape from the nonpreferred stimuli involved in the EEG procedure. If the child tries to avoid or disrupt the placement of the EEG sensors and leads, the therapist gently physically interrupts the behavior and redirects the child to engage in alternative behavior that is incompatible with escape, but compatible with the EEG procedure (e.g., telling the child "hold your train" while handing

the object to the child, or "press the buttons" while redirecting the child's hands to an electronic toy).

Counterconditioning involves procedures to decrease conditioned anxiety by gradual exposure to the feared or nonpreferred stimulus while keeping the patient actively involved in a distracting, relaxing, or otherwise pleasurable activity. When being prepared for an EEG, the child is gradually exposed to the EEG material and routine while participating in a preferred activity such as watching a cartoon or playing with a toy. This pairing of nonpreferred stimuli with preferred stimuli helps the child replace negative associations between medical stimuli and discomfort with a positive association between the EEG stimuli and a preferred activity. This new positive association counteracts conditioned anxiety that developed during prior negative medical experiences or failed EEG attempts.

Shaping refers to using differential reinforcement to strengthen successive approximations of a target behavior. Using carefully planned, gradual exposure of the child to the equipment and routines, he or she is taught the specific behavior necessary for cooperation with the EEG procedures. During this shaping process, reinforcement is provided contingent on progressively more acceptable behavior, whereas reinforcement is withheld whenever unacceptable behavior occurs. The training progresses within and across sessions at a pace that is adjusted to the child's availability for training, demonstrated ability to follow instructions, observed anxiety, and escape/avoidance behavior. Just as presented above concerning training for radiation therapy, the pace of training for EEG also should challenge the child by teaching and requiring new behavior but not overwhelm his or her current ability to cope and self-regulate emotion. The specific number of training sessions must be individualized according to the child's progress. It is important to note that attempts to avoid or escape the EEG sensors do not necessarily preclude the completion of steps in the task analysis. In many cases, children exhibit these behaviors but can be redirected and subsequently do tolerate completion of additional steps in the task analysis. Furthermore, while a child may not exhibit high levels of escape/avoidance behavior, the therapist may determine that the observed level of distress or anxiety is too high for additional steps to be attempted without overwhelming the child's ability to cope and causing him or her to lose control and have a tantrum. The objective is always to conclude the session on a positive note, with successful cooperation with the most advanced step in the task analysis that can be accomplished while keeping

the child predominantly happy and ending the session with child success and positive reinforcement.

Caregiver and Medical Staff Training

Caregivers and medical staff involved in the EEG/sleep study procedure should be provided with behavioral training to increase the consistency with which individuals interact with the child during the procedure. The behavior therapist models appropriate verbal interaction, differential reinforcement, and escape extinction procedures during each session for the caregivers. In addition, these strategies are reviewed during a brief preparatory meeting with the medical staff who will be conducting the EEG study. If possible, a mock EEG should be conducted in the EEG lab, with the EEG technologist first observing and assisting the behavior therapist and then switching roles to facilitate generalization of treatment gains to the actual EEG setting and staff. The same preferred activities or objects used during behavioral training sessions should be provided during the actual EEG procedure. Medical staff members are asked to have all equipment ready and available rather than having the child wait for the application of leads to begin while staff gather supplies. If the wait for the procedure to begin is too lengthy or unstructured, child frustration and distress are likely to increase.

Ultrasonography and Echocardiograms

Ultrasonography is a noninvasive diagnostic test that involves no ionizing radiation and instead uses very high frequency sound waves produced by a handheld device called a *transducer* and bounces them off of the targeted body part or area being examined. The waves reflected back are detected by the transducer and sent to a computer that measures and processes the data to generate an image of organs and other body structures. The image is displayed on a computer monitor and can be saved as an electronic digital image file on the computer. A sonogram, echogram, or ultrasound is an image or series of recorded images (video) from an ultrasound test. For ultrasound testing, a clear gel is applied to the skin and the transducer is then moved back and forth over the area being examined. Ultrasound is used for looking at organs and other solid or fluid-filled structures. Most people are familiar with ultrasonography because of its routine use in prenatal examination of the fetus in pregnancy.

Another type of ultrasonography that is in common medical use is the echocardiogram, which uses ultrasound to examine the heart and its adjoining blood vessels. Echocardiography is used as a noninvasive alternative to a cardiac catheterization for examining heart and blood vessel anatomy and function (movement, pressures, blood flow). Its results can often be used to determine if more invasive diagnostic testing requiring heart catheterization is warranted.

Echocardiography is a mainstay diagnostic and monitoring procedure in pediatric cardiology. It is used to diagnose congenital defects in heart and blood vessel anatomy (heart murmur, valve or vessel malformation, etc.) and function (movement of the myocardium, blood flow and heart chamber pressures) in both congenital and acquired cardiac disorders (e.g., cardiomyopathy). For children with cardiac disease, echocardiography also is used to monitor changes over time, plan for surgical intervention, and evaluate the effects of surgery or other medical intervention.

Most children under the age of 3 are sedated for echocardiography, and many children who are older with developmental disability or behavioral difficulties are sedated either because they have failed to cooperate with this examination or it is assumed that they will be unable to cooperate. However, as discussed above with respect to other procedures, sedation is not without its disadvantages and complications. For example, 5%–13% of children may be inadequately sedated, and 9% experience at least minor complications such as emesis, oxygen desaturation, or arrhythmia.[29-30] In order to cooperate with echocardiography, a child must remove clothing from the waist up (may be covered with a gown or sheet), get on an examination table, and lie back in the supine position. Adhesive-backed heart rhythm monitoring sensors are then attached to the chest, and wire leads are connected to the sensors. A clear gel is placed on the chest to facilitate sound wave conduction and to lubricate the transducer, which is placed on top of the gel and makes direct contact with the skin as it is moved over various locations on the chest and neck to acquire different views of the heart wall, chambers, valves, and vessels. The behavioral challenges for a child during echocardiography are similar to those for the other procedures described in this chapter: instruction following, compliance with positioning and motion control, and tolerating unfamiliar, aversive stimuli (physical touch, texture and temperature of the gel, reduced room lighting, etc.). The steps of the procedure, the behavioral demands, and the associated stimulation can be task analyzed for the purposes of gradual exposure, counterconditioning, and shaping of cooperation and

TABLE 7.3 Echocardiogram Task Analysis and Data Sheet

Step/Procedure	Cooperation? +=yes −=no	Negative Vocalization? +=yes −=no	Escape/Avoidance Behavior? +=yes −=no
Enter examination room			
Sit on gurney			
Lie back in supine position			
Examine with stethoscope			
ECG sensors attached			
Blood pressure left arm			
Blood pressure right arm			
Blood pressure left leg			
Blood pressure right leg			
Dry transducer on chest			
Transducer with gel on chest			
Overhead lights out			
Transducer with gel 10 seconds			
Transducer with gel 30 seconds			
Transducer with gel one minute			
Transducer with gel two minutes			
Transducer with gel five minutes			
Transducer with gel 10 minutes			
Transducer with gel 20 minutes			
Pressure below sternum			
Pressure over carotid area			
On side, head tipped back			
Head tipped, press at throat			
Other			
Other			

motion control. An example task analysis for echocardiography is presented in table 7.3.

7.4. SUPPORTING STUDIES

Training for Neuroimaging (MRI Scans)

The author and colleagues[4] first used antecedent management (modified the scanning environment to give it a cartoon façade) along with contingent videotaped entertainment and token reinforcement for gradually improving cooperation and motion reduction in pediatric patients ages 5 and up. These patients had developmental disabilities and/or psychiatric diagnoses but were not acutely ill, in pain, or in need of MRI for urgent diagnostic purposes. Among this physician-referred group, 94% were successful in meeting a movement criterion of 2 mm per second or less during a 20-minute simulated scan, and these individuals successfully cooperated with their subsequent actual MRI scans without sedation, resulting in good-quality images.

Subsequently, we studied four typically developing children using simulated MRI scans to measure the effects of our training protocol involving both antecedent changes in the imaging environment and operant conditioning of movement inhibition (lying still).[5] The data from our study are displayed in figure 7.1. That study experimentally demonstrated functional control over normal children's movement during simulated MRI scans and conducted a partial component analysis of our procedure. The participants were typically developing children (two boys and two girls, ages 5–6) who, with parental consent, volunteered for 20-minute simulated scans using an inactive scanner. The helmet-like "head coil" of the scanner partially covered the child's face, with vision possible through a mirror attached to the head coil. Head supports and safety straps used during MRI were gradually introduced during the simulations. Audiotaped scanner noises were played, and their volume was gradually increased to that of the active scanner. Movement was measured with a custom-made apparatus that was connected to the child's forehead by nylon string and an adhesive patch. Head movement activated the apparatus, which interfaced with a PC computer and measured head movement in millimeters per second.

The child was positioned in the scanner and told to hold still. The apparatus was attached, and three experimental conditions were presented. In the baseline condition, the environment was arranged according to usual

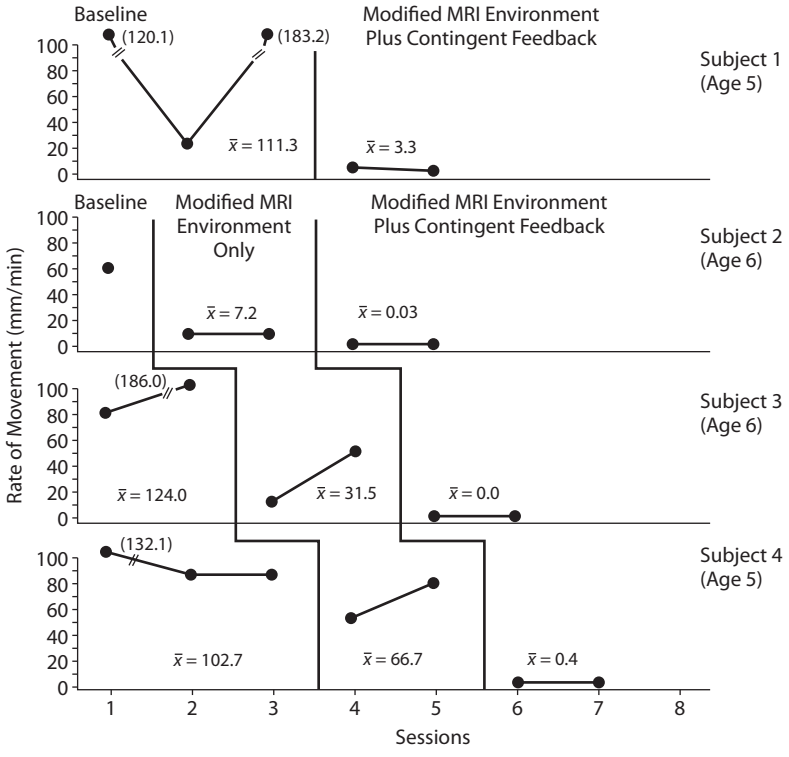

Figure 7.1 Data for four 5- to 6-year-old children participating in behavioral training for an MRI scan using a mock scanner. During baseline, no environmental modification or behavioral intervention was provided. Introducing environmental modifications alone for Subjects 2, 3, and 4 resulted in movement reductions that did not reliably meet the criterion for successful imaging, and movement increased during the second session of this condition for Subjects 3 and 4. The combined environmental and behavioral intervention immediately reduced head movement to very low rates for all subjects.
Source: Slifer, K.J., Cataldo, M.F., Cataldo, M.D., Llorente, A.M., & Gerson, A. C. (1993). Behavior analysis of motion control for pediatric neuroimaging. *Journal of Applied Behavior Analysis*, *26*, 469–470. Reprinted with permission from the Society for the Experimental Analysis of Behavior, Inc.

clinical practice. There was no entertainment or feedback during the mock scan, and a toy was given at the end of the scan. During a subsequent "modified MRI environment (noncontingent cartoon) condition," the scanner was covered with a cartoon façade, and the child could choose and watch a cartoon videotape reflected on the head-coil mirror, with the soundtrack played through earphones. Once again, a toy was given at the end

of the mock scan regardless of the child's behavior during the mock scan. During the final "modified MRI environment plus contingent feedback condition," operant conditioning was added. In this condition, viewing the cartoon videotape was made contingent on the child holding still (restricting head movement to 2 mm per second or less). Any greater amount of head movement automatically stopped the videotape for a three-second "time-out from positive reinforcement." Compliance also was reinforced with praise and food items that could be both eaten after the scan and used as tokens to acquire a toy (e.g., "You must earn 20 Goldfish crackers to get a toy after the scan").

Introducing environmental modifications alone resulted in movement reductions, but the children did not reliably meet the criterion for successful imaging. Movement actually increased during the second session of this condition for some participants. When the combined intervention was introduced, head movement was quickly reduced to very low rates, thus supporting the use of operant conditioning to teach children to cooperate with MRI and thereby avoid sedation.

This approach is most useful for diagnostic procedures that are not clinically urgent, such as those associated with long-term management or rehabilitation of children who are medically stable. It is not appropriate for children who are acutely ill, in significant pain, have acute impairment of consciousness, or require emergency diagnostic procedures.

A third study[31] compared the use of the behavioral training protocol described above with the use of sedation to ensure motion control for MRI. The study included 133 children and adolescents ages 4–18 undergoing rehabilitation from severe traumatic brain injury. One hundred of the children received an average of two 20-minute behavioral training sessions on a mock scanner in preparation for their MRI and received no sedation. Thirty-three others received no behavioral training but instead were sedated for their MRI using intravenous pentobarbital 4–6 mg/kg of body weight. The images resulting from the MRI scans were compared between groups using a three-point rating scale across five image characteristics: (1) motion artifacts, (2) sharpness of organ borders, (3) certainty of identifying or excluding pathology, (4) certainty of determining extent of pathology, and (5) overall image quality. The inter-rater reliability of the scale was excellent (mean Kappa coefficient was 0.7 based on Cohen's classification).[32] Of the 15 statistical comparisons, 14 showed no significant difference between the behaviorally trained group and the sedation group. The

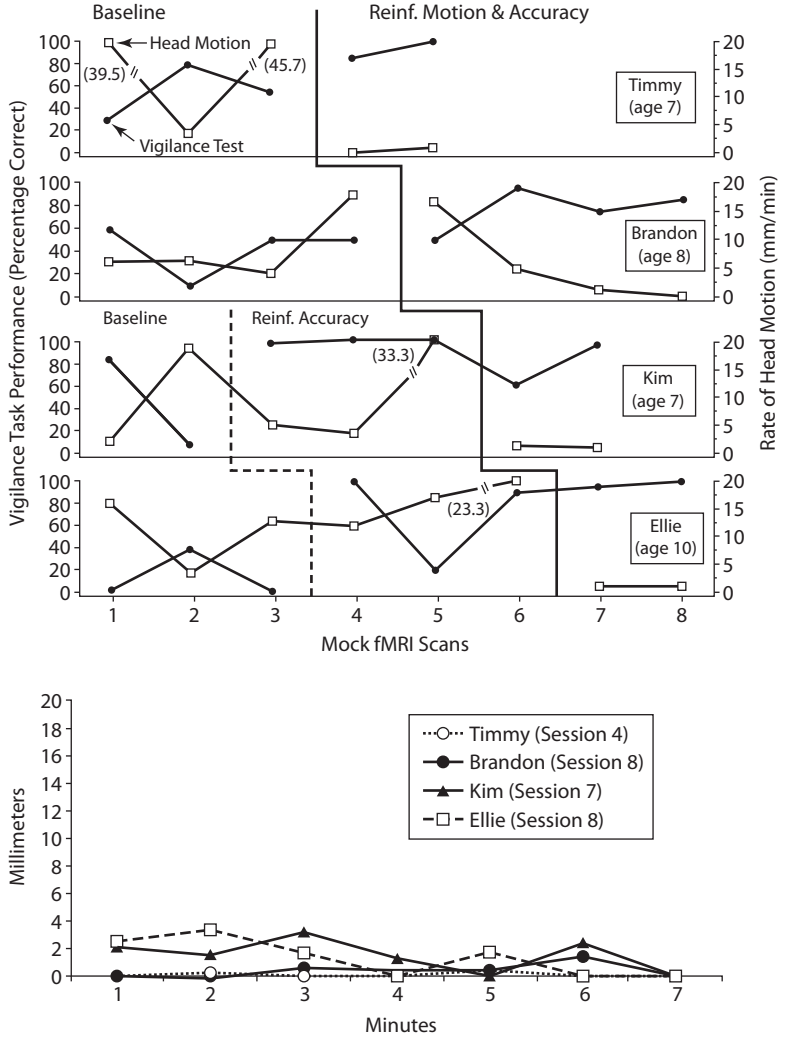

Figure 7.2 Top panel displays the percentage correct on the vigilance task (*filled circles, vertical axis on the left*) and rate of head motion in millimeters per minute (*open squares, vertical axis on the right*) across baseline and reinforcement conditions during simulated fMRI scans. The bottom panel displays the minute-by-minute head motion measured in millimeters during each child's best performance in the reinforcement condition. *Source*: Slifer, K.J., Koontz, K.L., & Cataldo, M.F. (2002). Operant contingency based preparation of children for functional magnetic resonance imaging. *Journal of Applied Behavior Analysis*, *35* (2), 191–194. Reprinted with permission from the Society for the Experimental Analysis of Behavior, Inc.

one comparison in which sedation showed significantly better image quality than behavioral training was overall image quality for the third of three imaging sequences. The sedation group had better average overall image quality only for these images that were acquired last, when the children in the behavioral training group were most fatigued. This study indicated that behavioral training is an acceptable alternative to sedation for ensuring cooperation and motion control for nonurgent brain imaging of children and adolescents with acquired intellectual disability, while acknowledging that image quality may deteriorate in some cases as the time required for imaging increases.

We conducted another study[6] to demonstrate that behavioral procedures may be used effectively to train motion control and task performance in children undergoing a special type of MRI procedure called *functional magnetic resonance imaging* (fMRI), which is used to study brain function during cognitive and behavioral tasks (thinking and doing tasks such as symbol recognition, picture matching, and problem solving). For a successful fMRI study to be completed, accurate task performance and control of head movement are required simultaneously. The results of the study are shown in figure 7.2.

When a positive reinforcement contingency was applied simultaneously to holding still and vigilance task performance, accuracy increased on the vigilance task and head movement decreased to the very low level necessary for successful fMRI. In the time since this study was published, the author and colleagues have successfully trained numerous children for fMRI studies using the same protocol. While fMRI is primarily a research tool at this time, the study discussed above further supports the effectiveness of behavioral training for children who need medical procedures with strict compliance and movement control requirements.

Training for Radiation Therapy

The author and colleagues[17] developed and demonstrated the utility of an approach to training children to cooperate with radiation therapy based on the principles of learning and behavior employed within the field of applied behavior analysis. They used behavioral training techniques to desensitize preschoolers and children with special needs to the radiation treatment protocol and to teach them motion control in order to cooperate with therapy. In this pioneering study, data were presented for children between the ages of 3 and 7. Eighty percent benefited from the behavioral

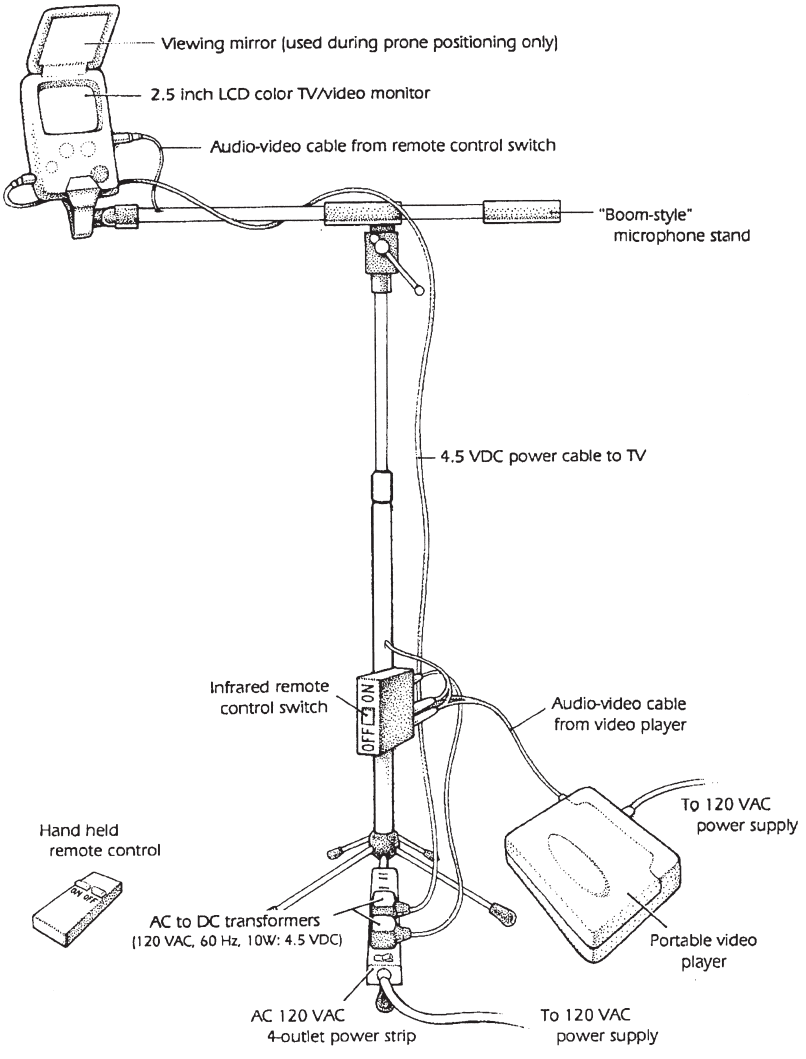
Viewing mirror (used during prone positioning only)
2.5 inch LCD color TV/video monitor
Audio-video cable from remote control switch
"Boom-style" microphone stand
4.5 VDC power cable to TV
Infrared remote control switch
OFF
ON
Audio-video cable from video player
To 120 VAC power supply
Hand held remote control
AC to DC transformers (120 VAC, 60 Hz, 10W: 4.5 VDC)
Portable video player
AC 120 VAC 4-outlet power strip
To 120 VAC power supply

Figure 7.3 Components and wiring configuration of the video display apparatus. *Source*: Slifer, K.J. (1996). A video system to help children cooperate with motion control for radiation treatment without sedation. *Journal of Pediatric Oncology Nursing, 13*, 91–97. Reprinted with permission from Sage Science Press, U.S.

program and subsequently cooperated with their radiation treatments without the need for repeated sedation or anesthesia.

A follow-up study[18] developed and demonstrated an apparatus to display video cartoons and movies during behavioral training, radiation therapy planning, and daily treatments (see figs. 7.3 and 7.4).

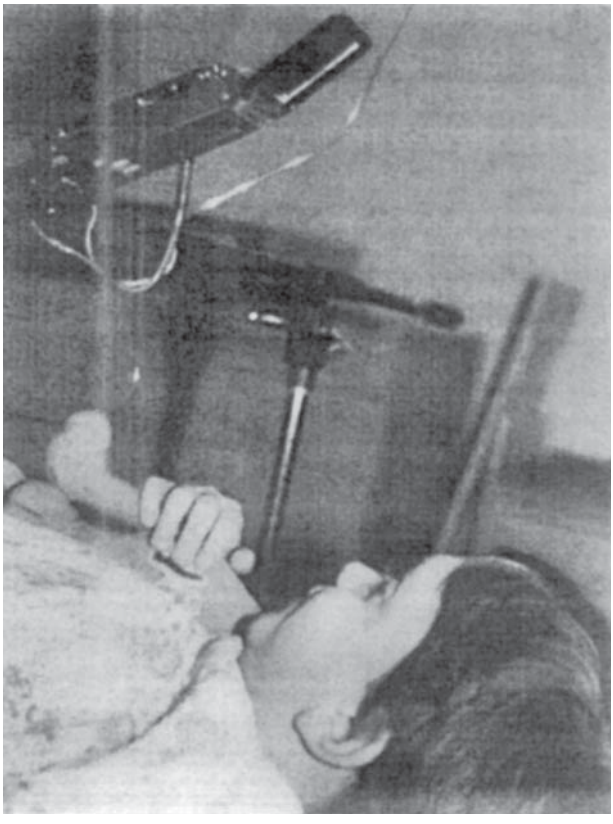

Figure 7.4 A child viewing the video display supported by the apparatus during radiation treatment planning. *Source*: Slifer, K.J. (1996). A video system to help children cooperate with motion control for radiation treatment without sedation. *Journal of Pediatric Oncology Nursing*, *13*, 91–97. Reprinted with permission from Sage Science Press, U.S.

With behavioral training and video distraction, 9 of the 11 children were able to avoid any sedation for daily treatments, and the 10th child was able to avoid general anesthesia for his last 10 daily treatments.

Training for EEG and Sleep Studies

The results of clinical research by the author and colleagues[20] suggest that the behavior therapy protocol described above is successful in improving the compliance of children with autism or other developmental disabilities

with EEG procedures. An EEG technologist or other professional who is willing to undergo training provided by a behavior therapist on these specific behavioral techniques would likely be able to perform this intervention effectively. On average, the patients in our study required six sessions of individual therapy before they were able to successfully cooperate with the EEG procedure.

Children with epilepsy undergo repeated EEG studies throughout their lifetime to monitor their disease and the effects of treatment. Providing behavioral intervention not only allows for success with the immediate procedure but also provides the child with a skill that facilitates future EEG examinations and may generalize to other types of medical procedures. Some children may require retraining prior to a subsequent EEG procedure, but the amount of training required will likely be less given prior success.

After being trained on this protocol, parents may be able to implement these procedures in preparation for other medical procedures requiring their child to cooperate and hold still. However, it should be acknowledged that some children with severe cognitive deficits or severe disruptive behavior may not be able to respond to behavioral treatment quickly enough for it to be a realistic solution (e.g., if test results are needed urgently or if caregivers cannot continue to bring the child to training sessions).

In related work, the author and other investigators[33] used a similar behavioral protocol to assist children with disabilities participating in a study investigating the effects of a cholesterol-lowering medication on patients with Smith-Lemli-Opitz syndrome (SLOS), which is a developmental disability syndrome resulting from an inborn error of cholesterol biosynthesis[34] and is associated with multiple congenital malformations. Cholesterol-altering therapies have been used to improve physical growth, and effects on behavior are being studied. Behavioral characteristics noted in this population include cognitive deficits, sleep cycle disturbance, sensory reactivity, irritability, aggression, and self-injurious behavior. As many as 46% of these individuals meet diagnostic criteria for autism.[35-36] In our recent study,[33] behavior therapy was provided to facilitate participants' cooperation with an overnight EEG examination. The participants consisted of 10 males and 7 females ranging in age from 4 to 17. On average, the children were functioning in the lowest categories on cognitive and adaptive testing, and their sensory processing and emotional-social responses were below average. The children participated in one 60-minute

training session conducted during a mock EEG. Behavioral methods included task analysis, differential reinforcement, and escape extinction as discussed above. Because of time constraints allowing only one 60-minute training session on the day prior to the actual procedure, therapists were not able to train children to 100% compliance prior to the actual EEG, yet the majority of children were able to tolerate all steps of the actual overnight EEG. Even with their diminished functioning level and only one training session, 53 percent of children tolerated all steps of the training task analysis, and subsequently 88% of participants tolerated all of the steps of the actual overnight EEG procedure, thereby further supporting the utility of the behavioral protocol for training children to cooperate with both routine and overnight EEG monitoring.

While still preliminary in nature, the results of the two EEG training studies described above add further empirical support for the general utility of behavioral interventions in the medical setting to increase compliance with various medical regimens as described throughout this book. Of course, because these are multicomponent interventions, we do not yet know if all components are necessary to achieve the same successful results. Additional research is needed to determine the essential components of the protocols described here.

Behavioral Training for Ultrasonography and Echocardiograms

Very little research has been published about nonpharmacological interventions to help children tolerate echocardiography without sedation. A search of the literature produced one study[37] that tested the effects of providing entertaining videotapes to watch during echocardiography for young children ages 5–64 months (mean age 18.6 months). These were children who, because of excessive activity level, lack of cooperation, fear, or crying, normally would have been sedated. Yet with the provision of video entertainment, complete examinations were obtained for 35 of the 38 children without sedation. Twelve of these patients subsequently underwent cardiac catheterization requiring sedation. There was a high degree of correspondence between pressure measurements obtained during their echocardiograms and the pressure measurements obtained during subsequent cardiac catheterization. This high correspondence of the results validated that high-quality results could be obtained with nonpharmacological methods for behavior management. Videotape viewing appeared to

help children cooperate and lay still, producing results that were quite accurate. In only 1 of the 38 cases was there a significant discrepancy in the pressure measurements obtained with videotape viewing compared with the sedated catheterizations.[37]

Although the pediatric psychology team at our institution has not systematically studied behavioral intervention for echocardiography, clinical experience supports the effectiveness of the same type of behavioral protocol used effectively for the various other procedures presented in this chapter. Data from the following case example are representative of our clinical success in teaching children to cooperate with unsedated echocardiography.

The child in this case example was a 4.5-year-old with a genetic syndrome that included congenital heart disease requiring two open-heart surgeries in his first year of life. He had significant developmental delay and a history of mild aggression and self-injury (head banging). To monitor his cardiac function, he required four extremity blood pressure measurements and echocardiography on a regular basis (approximately every six months). He had a history of behavioral distress when these assessments were attempted and had been unable to cooperate with these assessments unless he was under general anesthesia. The child was referred by his pediatric cardiologist to the author for behavioral training so that he might be able to undergo the necessary procedures without the need for sedation or anesthesia.

The child and caregivers were seen for a total of five mock echocardiograms that included the procedures described in table 7.3. The first three sessions were conducted in an outpatient therapy room in the psychology department where a gurney, computer monitor, portable blood pressure cuff, pulse oximeter, hospital gown, examination gloves, and mock transducer were used to simulate the echocardiography routine. In this case the mock transducer consisted of a narrow TV remote control covered with an examination glove to allow for sanitary use and cleanup after contact with the gel required for the procedure. The remaining two sessions were conducted in the heart center using the actual echocardiography equipment at the end of the day when no longer in use for actual clinical assessments. The child was provided with a favorite videotape to watch as both a distractor and positive reinforcement during the mock procedure, allowing for gradual exposure, counterconditioning, and shaping as detailed for the other procedures described earlier in this chapter. During the last mock procedure, the heart center staff member who would conduct the actual

echocardiography was introduced, faded into the routine, and ultimately took over with the actual transducer to simulate what would occur when the child returned for the actual echocardiography. One parent participated in all of the training sessions by providing social reinforcement and tokens for child cooperation, as directed by the therapist. At the end of each session, the child selected a small toy from an array, which was then presented as the backup reinforcer for the tokens earned during the session.

The data obtained on the child's behavior during these training sessions and the subsequent actual procedures are shown in figure 7.5. As training progressed, the amount of time that the child could cooperate without attempting to escape the procedure increased from 4 minutes during the initial session to 35 minutes during the actual echocardiography, and attempts to escape or disrupt the procedure decreased from 36% of the task analysis steps in session 1 to 0% by session 4. During the actual procedures conducted in the heart center (session 6 in fig. 7.5), the child was able to cooperate successfully with the echocardiography routine, despite being uncomfortable with an active ear infection at the time.

After this initial demonstration case, the same protocol has been used successfully with a number of similar cases. Although no prospective study has been conducted to compare the behavioral protocol described here with a usual care or other control group, the results of the clinical work by the author and colleagues are encouraging. When considered together,

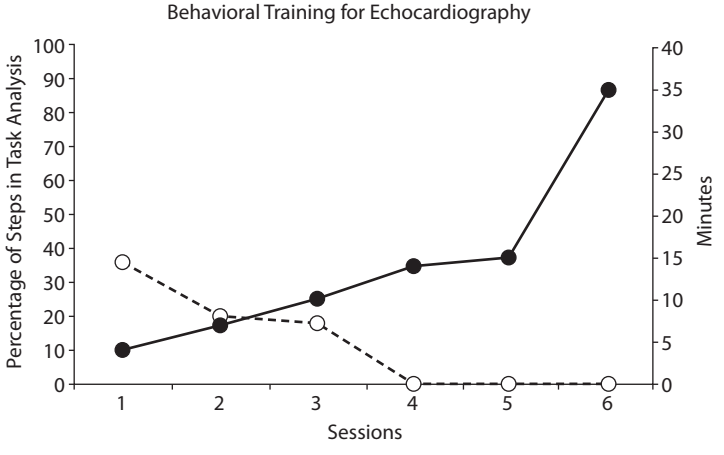

Figure 7.5 Percentage of task-analyzed steps during which the child attempted to escape or disrupt the echocardiogram (*open circles*) and number of minutes the child cooperated without attempting to escape or disrupt (*filled circles*).

the results of behavioral training for MRI, fMRI, radiation therapy, EEG, sleep studies, and echocardiography presented in this chapter support a successful approach that generalizes well across noninvasive, nonpainful pediatric procedures that may provoke fear and anxiety in a child yet also require cooperation and motion control. With the approach presented in this chapter, the potential is great for helping many more children avoid the unnecessary risks and inconveniences of sedation and anesthesia for these types of medical procedures.

KEY CONCEPTS

- Children with chronic health conditions often experience uncomfortable medical procedures repeatedly.
- Such procedures require the child to cooperate with positioning and to hold still for the duration of the procedure.
- Behavioral intervention to help children cope and cooperate with nonpainful diagnostic procedures should provide the following: (1) information about the sensations the child will experience and the behavior that will be required during the test, (2) real or simulated equipment to gradually expose the child to these sensations and behavioral demands, (3) specific instructions and opportunities to practice getting into and remaining in position, and (4) distracting activities to help the child cope with any aversive aspects of the procedure by diverting attention to these more preferred activities.
- Prior to attempting behavioral training for procedures, it is helpful to task analyze the procedure, assess the child's preferences to determine likely positive reinforcers, and assess the child's general compliance with caregiver instructions.
- If general compliance with adult instructions is poor, a period of general compliance training may be necessary before beginning exposure and counterconditioning for the medical procedure.
- There is growing evidence to support the successful use of behavioral training to prepare children to cope and cooperate with a variety of diagnostic tests, such as X-rays, CT scans, MRI scans, EEGs, sleep studies, and sonograms (ultrasound), without the use of sedation, anesthesia, or restraint.

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Cooperation with Vision and Hearing Tests and Treatments

IN THIS CHAPTER

- Vision and hearing tests have unique features that require systematic planning and preparation to prevent behavioral distress in young children and individuals with intellectual and developmental disabilities (IDD).
- The importance of early identification of vision and hearing impairments in childhood is discussed.
- Behavior analysis approaches to facilitating child cooperation and adherence with vision and hearing remedies are described from the literature and the author's clinical work.
- Task analysis, desensitization, and counterconditioning techniques tailored to these mildly invasive procedures are presented.
- The potential for behavior analysis methods to mitigate the negative developmental impact of early childhood sensory impairments is illustrated through discussion of relevant studies and recommended procedures.

8.1. PATIENT POPULATION AND TARGET PROBLEM(S)

The information in this chapter is relevant to infants, preschoolers, and early-school-age children, as well as all individuals with IDD. Sensory impairment in childhood may be part of a multiple-disability disorder or may occur in otherwise-healthy children. Severe sensory deficits in childhood may delay development of walking, talking, adaptive behavior, and socialization.[1] Early diagnosis and intervention can limit the impact of some of

these impairments. Furthermore, understanding the nature and severity of the deficit allows for adjustment in educational strategies to emphasize the child's strengths. However, it can be quite difficult to test sensory abilities such as visual acuity accurately in individuals with IDD and limited verbal skills.[1]

8.2. ASSESSMENT PROCEDURES

Pediatric Visual Disorders

The description of vision screening and assessment methods presented in this chapter is based on excellent chapters by other authors, the contents of which are presented in summary below.[2-3]

Vision screening and examination may be accomplished using examiner observations and eye charts or may require special equipment and specialist training. If the child is verbal and cooperative, or is nonverbal but can point to a figure on a card that matches the figure that the child is viewing on a distance chart, visual screening is possible. However, it cannot determine visual acuity with precision, only the range of the child's visual function. Many methods of vision screening and testing are currently available and have been well validated, and their appropriate uses have been summarized for pediatricians and other child health professionals.[4]

Recently a national survey of pediatricians was conducted to evaluate their practices with regard to preschool vision screening. Screening at age 3 was only done by 35% of pediatricians, whereas the percentages increased to 75% and 66% at ages 4 and 5, respectively. The most common barriers to screening were that it is too time-consuming, there is no specified reimbursement for doing the screening, and many children are uncooperative. Indeed, lack of cooperation was a major barrier because only 49% of the sample was cooperative enough for their screening results to be valid. Interestingly, the authors' suggested solutions involved purchase of different equipment and seeking a mechanism of reimbursement, but they did not consider the possibility that behavioral training might be helpful for increasing child cooperation with screening.[5]

Other authors have reported similar percentages of cooperation problems (42%) when screening typically developing 2- to 3-year-old children[6] and when attempting to screen children with IDD (51%).[7] In the latter study, the authors suggested that making the screening test simpler might be helpful but would result in more imprecise results. The suggestion was

referral to a pediatric ophthalmologist, but no information was given as to how the ophthalmologist would be better at managing cooperation problems. Again, in neither of these studies was the possibility of behavioral intervention considered.

Even when interaction with the child is limited by severe IDD, important clinical information can be obtained through direct observation of the child. Observation can determine if the child gazes at and fixes his or her eyes on objects, people, and faces and tracks movement in all directions or in some directions and not others.[2-3]

Restricted visual fixation or tracking indicates that more thorough evaluation by a pediatric ophthalmologist is needed. These tests also typically require more technical equipment and increasing levels of child attention and cooperation. Examples include the optokinetic nystagmus, preferential looking, electroretinogram, and visual evoked potential (VEP) tests.[2] Optokinetic nystagmus testing requires the child to look at a rotating cylinder with alternating black and white stripes that become progressively thinner. With the preferential looking technique, the infant or person with disabilities must look at test pairs and will typically show a preference for looking at one of the items in the pair. For example, a boldly patterned striped target will be preferred when paired with an equally illuminated blank target. Progressive pairs are shown to the child, and the stripes on the target card become progressively thinner, requiring greater visual acuity. An alternative approach varies the position of the visual stimulus on the test card, and the examiner notes where the examinee looks or points and whether or not the test stimulus is detected. Scoring is performed by direct observation of where the child's eyes look on each trial. This test does not require speech or specific object recognition, but it does require attention to the stimulus pairs.

In contrast to the two tests mentioned above, the electroretinogram test requires putting topical anesthetic drops and modified contact lenses in the patient's eyes and attaching sensing electrodes on the face and body. Lights are flashed in the eyes, and sensors in the lenses and electrodes record the child's responses. The electroretinogram is used to assess both light and dark vision and therefore requires the child to be adapted to the dark by wearing a blindfold for up to 30 minutes. This type of test requires the child to be able to cooperate with motion restriction and to tolerate the application of sensors and a blindfold. Therefore, the behavioral requirements of the electroretinogram are not unlike those required for the electroencephalogram (EEG) and polysomnography procedures described in the previous

chapter, but they are more challenging because of the special sensitivity of the eyes to drops, contact lenses, and a blindfold.

The VEP test is used to evaluate the neural pathway between the eye and brain in children who are believed to have cortical visual impairment. It is also used to test for visual acuity in infants and children with severe disabilities. The child is seated in front of a video monitor, and checkerboard patterns or lines of various sizes are alternated at varying rates. Scalp electrodes are attached to the back of the child's head to detect impulses from the underlying visual cortex of the brain. Again, child cooperation and tolerance of restricted physical movement, electrodes, and related tactile stimulation are necessary to obtain the full diagnostic benefit of the VEP. If the child is uncooperative or not attentive to test stimuli on the video monitor, a bright flash can be used as an alternative visual stimulus. Using the flash, an intact neural pathway between eye and visual cortex can be confirmed, but this method cannot be used to estimate degree of visual acuity, unless the child can attend to the more complex and alternating visual stimuli presented on the video monitor.[2]

Pediatric Hearing Disorders

Between 10% and 15% of U.S. school children fail school hearing screening tests, and 1.8% of these children under the age of 18 have hearing impairment.[8] The information about pediatric hearing loss summarized below has been presented in greater detail elsewhere.[8] However, the following summary provides a helpful introduction and review of the topic.

There are many types of hearing impairments, which are classified by where in the auditory system the pathology is located. Malfunction of the outer or middle ear is described as "conductive hearing loss," malfunction of the cochlea or auditory nerve is referred to as "sensory neural hearing loss," and malfunction in the part of the brain that processes input from the ear and auditory nerve is referred to as a "central auditory processing disorder." There are also individuals with "mixed hearing loss," in which both conductive and sensory neural components are affected.

For infants and children, the prevalence of severe or profound hearing loss has been estimated to be 2 in 1,000. The etiology of these disorders is roughly one-third genetic, one-third acquired (from anoxia, prematurity, ototoxic drugs, trauma, or infection), and one-third due to unidentified causes. National Institutes of Health committees have recommended universal screening for hearing loss within the first three years of life, and a

child's hearing can actually be tested as early as within 24 hours of birth. Assessment in infancy is accomplished by "observation audiometry." This type of testing can detect hearing loss, but not the type or severity. This basic procedure involves the examiner sounding a noisemaker such as a bell or horn at up to 90 db of volume near the infant and then observing the infant for any change in behavior such as limb movement or eye widening. The occurrence of a consistent response can rule out severe or profound hearing loss. However, failure to respond could also be due to environmental noise or child habituation to the test stimulus. For these reasons, the preferred method for infant hearing screening is evoked otoacoustic emissions testing (EOAE). EOAE is a rapid, noninvasive, and inexpensive method of assessing cochlear function which involves sealing the ear canal with a plastic probe that includes a microphone and receiver. Then, a series of clicks and tones of varying frequencies are introduced into the ear canal, and the microphone records responses evoked from the cochlea.

Another related method is auditory brainstem response audiometry (ABR), which is also referred to as brainstem auditory evoked response (BAER) testing. This type of testing requires the attachment of EEG electrodes to the forehead and behind the ears. The child is then exposed to auditory stimuli of varying frequency and volume in order to test the cochlea, auditory nerve, and brain pathway. Child cooperation is only required in terms of tolerating and not resisting the electrodes, and if necessary the child can be asleep or sedated and the results are still valid. These methods are also useful for assessing older children with IDD.

Formal behavioral hearing tests provide specific diagnostic information. To do so, the methodology and techniques must be adapted to the child's developmental level. For example, in visual reinforcement audiometry (VRA) the child is conditioned to anticipate the appearance of an animated toy whenever an acoustic test stimulus (tone or voice) is presented. The frequency and volume of the sound are then systematically manipulated in order to test hearing sensitivity. After the initial training period, the toy appears only after the child has turned toward the sound.

Another type of testing that is a variation of VRA employs the conditioned orienting response (COR). Once again, the child is required to localize the sound source of the test stimuli. However, as children advance in age and developmental level, the assessment methodology becomes more complex and a greater degree of child cooperation is required. For example, in conditioned play audiometry, used for children between ages 2.5 and 4, the child must wear earphones and is taught to perform a specific play

behavior (stack blocks, put rings on a peg) in response to hearing the auditory stimulus. Beginning at around age 4, many children can follow instructions to press a button or raise a hand in response to hearing the auditory stimulus.

Still other procedures are required to differentiate the type of hearing impairment. For example, to differentiate between conductive and sensory neural hearing loss requires comparing results obtained using air conduction testing with earphones or speakers with results obtained on the same test using bone conduction testing in which a vibrator is placed on the mastoid bone just behind the child's external ear. Although not discussed further here, it should be noted that testing higher levels of auditory cortical functioning requires even more complex psycholinguistic tests, and these depend even more on the cooperation of the child being examined.[8]

8.3. INTERVENTION PROCEDURES AND SUPPORTING LITERATURE

Behavior analysis methods have been used to assist in the assessment of vision in children with developmental disabilities.[9–11] Noting that researchers in animal psychophysics had been measuring vision in animals for years, one investigator[9] devised a procedure using successive discrimination to assess vision in children who were nonverbal with intellectual disability or brain injury. The children were taught to discriminate left- and right-facing Snellen E symbols (the symbols used for typical vision screening and testing) through reinforcement of bar-press responses when one orientation was presented and no reinforcement (extinction) when the other orientation was presented. The size of the Es and the distance between child and stimuli were varied systematically and allowed the investigator to determine reliable vision thresholds for four children who previously were unable to be tested. However, this procedure required between 7 and 106 hours of training, depending on the child.

Other investigators[11] used a simultaneous discrimination procedure for measuring subjective visual acuity in 11 nonverbal children with autism or other mental disorders. They employed a stimulus fading procedure to train a visual discrimination between different visual symbols differing in their orientation (Snellen Es). The children were required to view a visual symbol on a sample card and then view two choice cards from a designated distance, and finally to approach and point to or pick up the one of the two choice cards with the same symbol and orientation as the sample card.

Praise and edibles were used to positively reinforce correct choices, and incorrect choices were not reinforced. During training, the density and orientation of the cards were varied until the child's performance met the training criterion of 5 consecutive correct choices in 15 trials. During the test phase, pairs of choice cards with successively smaller Snellen E symbols were presented until the child failed to meet the criterion of five consecutive correct choices in eight trials. Each of the different-sized Snellen Es had a corresponding visual acuity ratio (20/360, 20/200, 20/100, etc.). The acuity ratio at which the child met criterion on three separate presentations was considered the child's subjective binocular distance vision acuity.

The investigators used the procedures summarized above to test 11 nonverbal autistic or mentally impaired children and also to validate the procedure by testing four verbal nonimpaired children. Eight of the 11 nonverbal children were successfully tested in one to three sessions of 30–90 minutes. Two of these children were identified as having significant visual acuity losses. The validity assessment showed that this procedure produced comparable results to a standard eye chart method with a verbal child. While these procedures proved effective, they were time-consuming and thus only practical for children whose vision could not be successfully tested in a more conventional manner.

More recently, some investigators[12] studied three children ages 4–6 with either a developmental delay or autism who scored "could not test" on a state-required vision screening. Assessment of the participants' performance during attempted vision screening identified both visual discrimination skill deficits and escape/avoidance behavior. Subsequently, the authors provided behavior analysis–based discrimination training, which included a stimulus preference assessment, matching-to-sample discrimination training, transfer of stimulus control procedures, differential reinforcement, and operant choice procedures. Escape/avoidance behavior was treated by fading in the duration of wearing glasses, escape extinction, and reinforcement of alternative behavior. The results of this study supported the effectiveness of the package of interventions for teaching compliance with the behavioral demands involved in vision screening across three young boys with IDD. Their compliance was maintained after behavioral training, and two of them subsequently passed the state-mandated vision screening administered by a certified technician. Training also produced generalized compliance, allowing two of the boys to cooperate with and pass their hearing screening tests without direct training.

Vision Impairments and Corrections

Severe visual impairment in typically developing school-age children is considered a low-incidence disability, affecting only 1% of this population.[13] However, when including more common, less severe conditions such as hyperopia, myopia, astigmatism, anisometropia, amblyopia, and strabismus, about 11% of typically developing 3- to 16-year-olds evidence ophthalmic disorders, and this increases to about 33% in children with IDD.[7] By some estimates, the percentage of children with developmental disabilities with significant ocular disorder is as high as 48%–50%.[2] By all accounts, the prevalence of these disorders increases very significantly in children with developmental disabilities. This is especially the case for children with cerebral palsy, epilepsy, cerebral abnormality, or a genetic syndrome (e.g., Down syndrome).[7] Despite these numbers and many available screening options, only about 21% of preschool-age children are screened for a potentially reversible developmental vision disorder such as amblyopia, and as a result, many children develop permanent visual impairment, with the most likely barrier being problems with obtaining child cooperation, especially in young, nonverbal, or developmentally delayed children.[4]

Amblyopia is a common form of abnormal vision in children, which is often referred to as "lazy eye," and in many cases it is reversible if promptly diagnosed and treated. The problem occurs because of disuse of one eye during development, resulting in reduced visual acuity. As a result of disuse, there is a lack of development of certain visual pathways in the visual cortex of the brain. Amblyopia usually develops before the age of 9 and occurs in approximately 2.5% of preadolescent children. The primary intervention is a prescribed schedule of "patching" the unaffected eye.[2-3] This involves intermittently covering the "good eye" with an eye patch in order to require the child to use the amblyopic eye.[13]

Patching exposes the child to novel sensory experiences, including a change in visual field and acuity, as well as the physical contact of the patch with the closed eyelid and the skin around the eye. In addition, because adhesive patches are typically used, the skin may itch, and there may be discomfort when the patch is removed.

Nystagmus is another common pediatric vision problem that is characterized by abnormal, repetitive, rhythmic oscillation of one or both eyes. The movement is usually horizontal in direction but can occur with many variations in direction, pattern, and frequency. Nystagmus can be caused

by ocular abnormalities, optic nerve damage, dysfunction of the retina, neurodegeneration, metabolic abnormalities, or damage to the visual motor control structures of the brain. Treatment for nystagmus may take a number of different forms, such as wearing prismatic glasses, eye muscle surgery, wearing special contact lenses, or medication.[13] As with eye patching, all of these procedures involve stimulation and behavioral demands that are commonly nonpreferred and aversive to children. Thus, successful treatment usually depends on child coping and cooperation in one form or another, and the assistance of a behavior analyst or therapist may be required to facilitate treatment adherence.

Strabismus is another common pediatric vision problem. It is a disorder in which the eyes are misaligned and do not work in a coordinated fashion. About 6% of children between ages 4 and 6 are affected by strabismus, and if untreated, between 30% and 50% of these children will develop amblyopia as a secondary visual impairment. The best way to describe strabismus is to elaborate on how it is diagnosed. A simple and efficient test for strabismus is the "corneal light reflex test." This test involves projecting a small light onto both of the child's eyes simultaneously while the child looks straight ahead. If the light reflected back from the eyes is asymmetrical or off-center in one eye, the child has strabismus. Another approach is the "cover-uncover test" in which the child looks at a visual target 20 feet away while the examiner covers one eye and inspects the other for movement. The presence of movement indicates strabismus. A variation on this approach is to cover both eyes simultaneously and then uncover both while observing for eye movement, which would indicate the presence of strabismus. If diagnosed, various treatment options are available to improve or correct the child's vision. These include lenses, prisms, occlusion, filters, orthoptics (vision training), prescription medication, and surgery. The primary treatments are surgery, injections, and vision therapy. Surgery may involve a series of operations to strengthen or weaken one or more of the six ocular muscles that control eye movement. Injections of Botox into these muscles may have a similar but temporary effect. These procedures can correct eye alignment problems but do not necessarily produce binocular vision.[2]

Vision therapy or orthoptics refers to training the eyes to work together to restore binocular vision and improve physical appearance. Although not painful, vision therapy involves the use of various instruments, interactive activities, and computer-assisted programs to provide patient feedback.[13]

Both diagnosing strabismus and treating it with vision therapy require the child to be cooperative and attentive.

Early intervention and treatment for the childhood vision problems described above increase the chances that the child's vision can be restored, often with no residual effects. As children age, however, it becomes increasingly more difficult to reverse the vision problems. Therefore, it is important to be able to help parents and ophthalmologists collaborate to accomplish early testing and interventions. Given that many aspects of diagnosis and treatment require the child's cooperation, and that behavior analysts specialize in teaching and motivating children to perform adaptive and cooperative behaviors, there is an important role for behavior analysts to play in the area of pediatric ophthalmology. Unfortunately, there is paucity of behavioral research and practice in this area; therefore, the number of children, particularly those with IDD, who might have been prevented from developing permanent visual impairments or whose visual acuity might have been improved by helping the child cooperate with diagnosis and therapy is unknown.

Past behavior analysis studies have been used to modify visual behavior. In particular, operant training has been used to modify visual acuity in individuals with myopia.[14–16] In this type of training, a combination of stimulus fading and reinforcement procedures was used. Letter stimuli were first presented at the farthest distance at which they could be identified without squinting, and then the distance was faded by a small amount each time the participant met a predetermined performance criterion, such as 10 consecutive correct discriminations. Correct responses resulted in positive verbal feedback, and incorrect responses were placed on extinction. This literature consistently reported improvements in the visual acuity of individuals with myopia. However, one study[16] showed that the change in acuity was more pronounced with letter stimuli specifically used for training and only partially transferred to untrained stimuli. Furthermore, refractive errors assessed on a weekly basis showed no change in the actual physiology of the eye (e.g., shape of eyeball or cornea). These results suggested that although the training could change vision-related behavior and visual acuity under some circumstances, it did not seem to have clinical utility for correcting the visual defect involved in myopia across environments as would be the case with prescription eyeglasses.

Of more obvious and practical clinical utility is the use of behavioral training to increase the tolerance and adherence of young children or

those with IDD with wearing prescription glasses to correct their vision defects. As mentioned in the study reviewed below,[17] some investigators have found that among residents at a facility for individuals with mental retardation who were prescribed glasses, only 59% were adherent with wearing their glasses after six months. Another 17% completely rejected their glasses, and 24% did not receive glasses because residential staff assumed that these individuals would not wear them.[17]

Another study[18] evaluated an intervention for promoting adherence with wearing prescription glasses in four individuals between the ages of 4 and 19 with intellectual disabilities. These participants included three boys with autistic disorder (ages 4, 14, and 19) and one girl with Down syndrome. Two participants had moderate intellectual disability, and two had severe intellectual disability. In this study, distraction and noncontingent reinforcement (NCR) were provided in the form of access to preferred activities. This intervention alone increased glasses wearing for one of the four participants. A package intervention was implemented for the other three participants. The package included NCR, response cost (removal of the preferred activity and caregiver attention for 30 seconds whenever the participant removed the glasses), and response blocking (physically blocking attempts to remove the glasses until no attempt occurred for five seconds). Functionally, this intervention allowed the participant to access preferred activities and caregiver attention, as long as the glasses were being worn. This combination was effective for increasing glasses wearing in these three participants, and by the end of the study, all four participants were wearing their glasses for essentially 100% of the times under observation.

The study design did not allow for a systematic analysis of which of the treatment components were necessary for the intervention to be effective. Even for the one participant who only received NCR, the exact cause of the behavior change could not be isolated because the behavior did not revert to baseline levels when the NCR was removed. Thus, the improvement may have been due to a process of sensory adaptation[19] as a result of repeated and prolonged exposure to the sensory experiences involved in wearing glasses. However, the sensory distraction of the NCR activity likely was necessary for the participant to tolerate the glasses long enough for the sensory adaptation to occur.

In the other three cases, the response blocking and response cost appeared to be necessary for the participants to learn to refrain from glasses removal long enough for sensory adaptation and/or counterconditioning

to occur. In any case, the combined intervention was not difficult to implement. This approach and a similar procedure involving differential positive reinforcement for wearing glasses and escape extinction of attempts to remove them (always blocking glasses removal and never allowing the participant to escape wearing the glasses) have been effective in other unpublished clinical cases under the supervision of the author of this book.

It is important to note that it would be impractical, if not impossible, for one caregiver to implement this type of intervention during all of the patient's waking hours. Therefore, this training can be conducted in sessions of gradually increasing duration until glasses removal becomes a low-frequency behavior. A suggested technique is for the caregiver to place the glasses on the patient and immediately provide positive reinforcement (praise and access to preferred activities such as video entertainment). The caregiver should control the wearing time by counting aloud or setting a timer. Exposure could begin with only a few seconds, if necessary, and gradually increase as the patient's tolerance improves. The use of a timer with a bell or beeper alarm is recommended because this helps the individual to learn that removal of the glasses is associated with the alarm (and passage of time) rather than contingent on any particular behavior by the child (escape from the glasses is time based and prompted by the alarm and verbal instructions from the caregiver, rather than based on the child's distress behavior). Clinical experience has shown that by using this approach the duration of glasses wearing can be increased relatively quickly in most cases.

8.4. CASE EXAMPLE

The clinical case study presented below is instructive with respect to the versatility and robust effectiveness of behavior analysis interventions to support children's ability to learn new skills and tolerate new sensations involved in the correction of sensory deficits. In this case a 7-year-old boy required desensitization and training to insert a corrective contact lens in his eye. The natural lens of the child's eye had been destroyed by a puncture wound several years earlier, but the cornea had healed. A contact lens was prescribed to compensate for the missing natural lens. However, as a result of the original trauma, multiple eye surgeries, being restrained for numerous medical procedures, and past unsuccessful attempts by medical staff and caregivers to insert the contact lens, the child was fearful of having the lens inserted. Although the prescribed lens was an extended wear

soft contact, the child still needed to tolerate lens insertion because of the need for periodic cleaning and disinfection, and because the lens often came out during sleep or play. The caregivers reported that any attempt to insert the lens resulted in a severe tantrum and associated panic symptoms (crying, flushing, sweating, and escape behavior). If he did not wear the lens regularly, it was likely that he would lose the residual eyesight in the affected eye because without regular focused stimulation, the associated neural pathway in the visual cortex of his brain would not develop normally. The goal of behavioral treatment was to desensitize the child to lens insertion and teach him the skills to manage his own lens, including inserting and removing his lens under direct caregiver supervision. As in the many other skill training interventions described in this book, the process of inserting and removing the contact lens was task analyzed (see figure 8.1).

Figure 8.1 shows the task-analyzed steps involved in lens insertion. It also displays how performance data were recorded for each step. The therapist recorded when a step was completed, if therapist prompting was required, and what fear rating on a three-point scale (0 = none, 1 = a little, 2 = very much) the child gave after completing that step. The therapist and child together developed a fear hierarchy and used it to plan sequential exposure that began with observing the therapist insert his own contact lens and then continued by having the child imagine touching his own eye, inserting the lens, and so on (see table 8.1).

Table 8.1 shows the exposure and desensitization hierarchy employed, the number of therapy sessions it took, and the child's self-reported fear rating for each level of the hierarchy. When prompted to attempt inserting his lens for a baseline probe, the child would not attempt any step in the task analysis. Subsequently, training began with therapist modeling, child rehearsal of procedures in the exposure hierarchy, and differential positive reinforcement for cooperation and performance of the procedure (or an approximation of it) by the child. After the baseline probe (see fig. 8.2), sessions focused on gradual exposure and shaping of the fine motor skills required to handle the lens and touch it to the eye. Figure 8.3 displays the number of steps in the task analysis which the child could complete with adult supervision but requiring no direct assistance, and sessions in which the lens was successfully inserted are marked with an arrow symbol. Over the course of these sessions, both the number of insertion trials gradually increased and he often unintentionally dropped the lens, necessitating repeated disinfection and rinsing. Beginning with session 10, a prosthesis was

Results of Initial Behavioral Probe

TASK ANALYSIS FOR CONTACT LENS SELF-MANAGEMENT
(LENS INSERTION)

Step	Completed?	Prompted?	Fear Rating None/ Little/ Very
1. Gets out required materials (lens case, saline, mirror, towel, bowl)	+	+	(0) 1 2
2. Spreads towel on tabletop	+	+	(0) 1 2
3. Sets up mirror	+	+	(0) 1 2
4. Removes tops from saline and lens case	+	+	(0) 1 2
5. Washes hands with soap, rinses, dries on towel	+	+	0 (1) 2
6. Sits at table in front of mirror	+	+	0 (1) 2
7. Sticks right index finger into lens case and removes lens	+	+	0 (1) 2
8. Rinses lens with saline	+	+	0 (1) 2
9. Positions lens open end up on center of tip on index finger of right hand	+	+	0 (1) 2
10. Holds upper eyelid up with left middle finger, lower eyelid down with right middle finger while looking ahead into mirror	+	+	0 1 (2)
11. Repeats step 10 while balancing lens on right index finger as in step 9	+	+	0 1 (2)
12. Repeats step 11, then gently inserts lens into right eye by pressing it straight onto eyeball	–		0 1 2
13. Blinks slowly several times by opening eye widely then closing entirely but not squinting	–		0 1 2

Figure 8.1 Example data sheet showing the task-analyzed steps involved in lens insertion along with the therapist's record of when a step was completed, when prompting was required, and what fear rating the child gave after completing each step.

TABLE 8.1 Exposure Hierarchy for Desensitization to Contact Lens Self-Insertion

Session	Procedure	Performed?	Fear Rating (0–2)
2	Observes therapist insert own lenses	+	0
	Imagines self touching eye	+	2
	Imagines self inserting lens	+	2
	Imagines self as cartoon hero inserting lens as "special weapon"	+	0
3	Imagines inserting lens	+	2
	Imagines lens already in place on eye	+	1
	Imagines touching eye as cartoon hero	+	2
	Touches closed eyelid	+	0
	Observes therapist touching own sclera	+	0
	Touches sclera of nontarget eye one second	+	0
4	Holds open eyelids of nontarget eye while touching innermost edge of lower eyelid for 60 seconds	+	0
	Touches sclera of nontarget eye one second	+	0
	Holds open eyelids of target eye while touching innermost edge of lower eyelid for 10 seconds	+	0
	Touches sclera of nontarget eye 10 seconds	+	0
5	Holds open eyelids of target eye while touching innermost edge of lower eyelid for 60 seconds	+	0
	Touches target eye on sclera for one second	+	2
	Touches target eye on sclera for seven seconds	+	2
6	Touches contact lens to target eye for one second as required for lens insertion	+	2
	Trial 2 (as above)	+	1
	Trial 3	+	2
	Trial 4	+	0
	Trial 5	+	1
7	Touches contact lens to target eye for one second as required for lens insertion	+	0

Note: Fear rating values: 0 = none; 1 = a little; 2 = very afraid.

improvised using the fingertip of a sterile examination glove placed on the child's right index finger. Approximately 3 mm of space was left between the tip of the child's finger and the tip of the prosthesis, so that when the tip of the prosthesis was depressed, it formed a concave surface that was

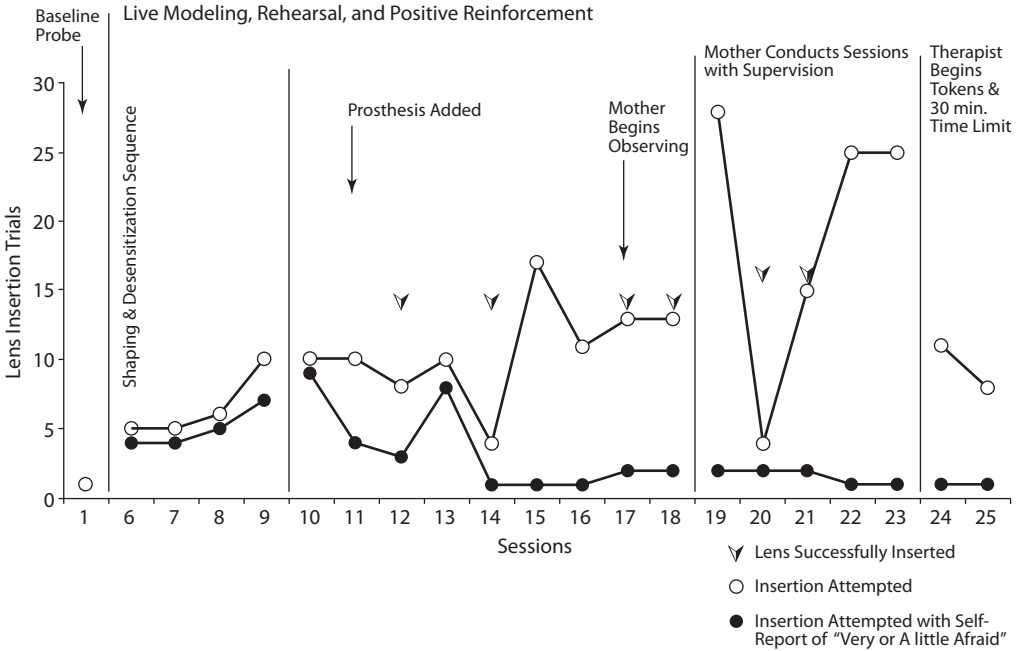

Figure 8.2 Graph showing the number (*vertical axis*) of lens insertion trials (*open circles*) and trials with child-reported fear (*filled circles*) and the number of training sessions (*horizontal axis*) for a 7-year-old boy learning to insert his own contact lens. The filled inverted triangles indicate the sessions during which he successfully inserted the lens. Data are plotted across baseline probe, therapist modeling, child behavioral rehearsal, and differential positive reinforcement for cooperation phases. Other environmental or procedural modifications are labeled with text above the data in relation to when they were introduced.

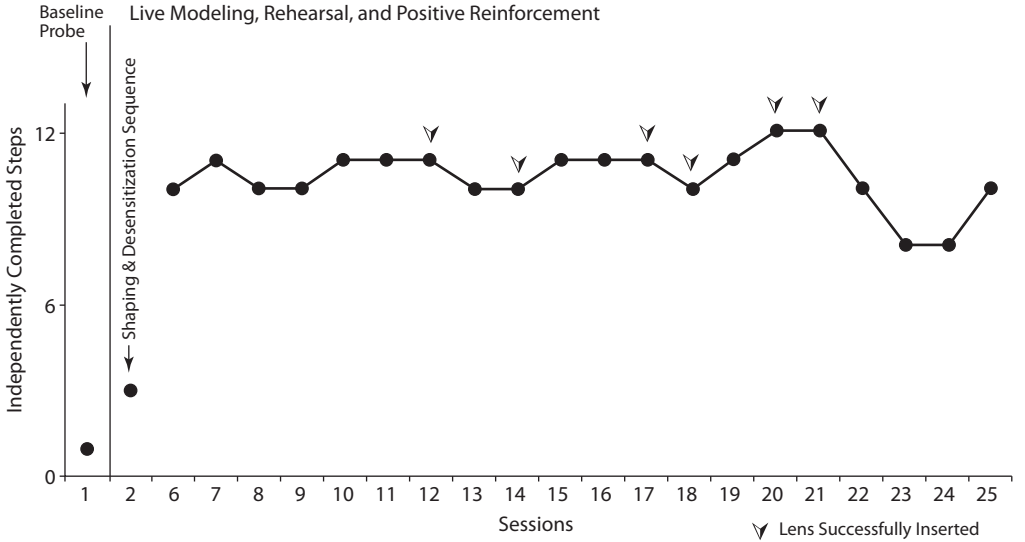

Figure 8.3 Graph showing the number of steps in the contact lens insertion task analysis which were completed independently by a 7-year-old boy (*vertical axis, filled circles*) and the number of training sessions conducted (*horizontal axis*). The filled inverted triangles indicate the sessions during which he successfully inserted the lens. Data are plotted across baseline probe, therapist modeling, child behavioral rehearsal, and differential positive reinforcement for cooperation phases.

filled with saline and caused the contact lens, when placed on it, to adhere to the child's finger tip, preventing him from dropping the lens.

During session 12, the child successfully inserted his lens, which was positively reinforced with a preferred toy as a prize. With continued rehearsal, the boy successfully inserted the lens during three more sessions (14, 17, and 18), the last two of which were observed by his mother. Although he was reporting minimal fear after session 14, these sessions required up to 10 trials before successful insertion. When his mother began conducting the sessions, the child continued to show little fear and was successful during two consecutive sessions. However, the number of trials required per session continued to increase. The increased number of trials appeared to result from increasing loss of motivation by the child to correctly perform the task. During the next two (and last two) sessions a token economy was introduced requiring the child to earn a target number of tokens within a 30-minute time limit to earn a tangible reward for the session. A successful insertion would have resulted in immediate award of all the required tokens. This procedure decreased session length and the number of trials to less than 10. However, the lens was not successfully inserted, and the family subsequently dropped out of treatment because of unrelated psychosocial problems. While the case was disappointing in outcome in that it is unknown if the child ultimately could have mastered the skill, it demonstrated that with adequate access to the patient and creative problem solving by the behavior analyst, children can learn to perform complex and challenging health-related self-care tasks with minimal distress. The case is also a good demonstration of the methods involved in task analyzing a complex self-care routine, shaping requisite skills, developing and implementing an exposure hierarchy, and tracking patient performance across training sessions. It also demonstrates that the success of behavioral intervention ultimately may be limited more by family psychosocial problems preventing access to the patient for training than by technical or procedural limitations.

An example of how applied behavior analysis methods can be used to assist with auditory assessment was published some 30 years ago.[20] These authors investigated a discrete-trials, operant-tracking, and descending-series procedure to determine the hearing levels of three individuals between the ages of 17 and 26 with profound IDD. This approach was designed for individuals who do not respond to verbal instructions and depends on the reinforcement of stimulus-detecting responses. Pretraining was conducted to establish stimulus control of the detection response. Stimulus

control refers to a pattern of behavior in which, because of a history of differential reinforcement, the target behavior occurs in response to a specific "discriminative stimulus" and does not occur in the absence of that stimulus (e.g., respond when the light is green, but not when it is red). In this study, stimulus control was established by reinforcing with an M&M candy when the participant pressed a lighted panel, but not in the absence of panel pressing or when pressing a dark panel. Once stimulus control was established with the lighted panel, then pure tones at 70 db volume and various test frequencies were added such that reinforcement was only provided when the participant pressed the panel after detecting the auditory test stimulus. The volume was systematically decreased until the participant made a detection error, and then the volume was increased by a small amount, and so forth. This process was continued until the participant's hearing threshold at various tone frequencies was determined. These operant conditioning–based methods appeared to be effective for testing "difficult-to-test" individuals.[20]

Interventions for Hearing Loss in Children

Treatment of hearing impairment varies depending on the type of problem diagnosed. Prescription antibiotics are used for intermittent middle ear infections. Minor surgery called *myringotomy* is used to treat chronic middle ear infection. This procedure involves making a small incision in the tympanic membrane ("eardrum"), to drain or suction out fluid, and then inserting tiny plastic tubes (pressure equalization or PE tubes) into the incision to maintain proper pressure equalization between the middle ear and the outside atmosphere even when the Eustachian tube is blocked by congestion.[8]

Treatment for permanent hearing loss may involve amplification using hearing aids or assistive listening devices or surgery. Hearing aids can be worn in or behind the ear, on the body, or on the mastoid bone. "In-the ear" aids are more limited in flexibility of the controls. "Behind-the-ear" aids can have more complex controls but are less desirable cosmetically and therefore may cause more patient nonadherence. "Bone conduction" hearing aids require wearing a small vibrator attached to the mastoid bone behind the ear with a headset or headband. Any of these hearing aids can only amplify the sound and do not make the sound more clear or distinct from background noise.[8] The physical sensation of the aid's placement on

the body and the background noise that is also amplified may be uncomfortable or even aversive to the child and may motivate avoidance and escape behavior in the child in order to terminate this nonpreferred stimulation. This can be a significant barrier to the child's acceptance of and adherence with the hearing aid. These characteristics of hearing interventions are often amenable to behavior analysis–based interventions to increase hearing aid tolerance and adherence.

In a study conducted over three decades ago, behavior analysts demonstrated how youth with IDD could be taught to put on and wear their hearing aids.[21] The investigators conducted two experiments with six students with multiple severe disabilities (5 males, 1 female) ranging in age from 15 to 22. The authors developed a 31-step task analysis that detailed the behavioral responses required to put on a hearing aid. The participants had been prescribed different types of amplification systems (air aid, body type, ear level, bone type); therefore, the participants did not all require every step in the task analysis. Outcome data were calculated as the percentage of relevant steps in the task analysis which the participant could complete without any trainer assistance. All of the students were able to acquire the skill. Two required intensive training on one step of the program which they had difficulty learning, but by the end of the study all students had acquired the skill of putting on their hearing aids. The second experiment conducted with three of the children replicated the successful training of the first three participants in experiment 1 and then assessed generalization to settings other than where the training was conducted. Using a single-subject experimental design (multiprobe baseline), the authors demonstrated that the students could put on their hearing aids without trainer assistance in environments where no training was ever conducted. Ultimately, all six students were able to perform their new skill in more than one setting and showed skill maintenance.[21]

While the above studies were conducted with teenage or older participants with severe IDD, clinical experience at our institution suggests that similar task analysis and step-by-step teaching with modeling, graded prompting, and differential positive reinforcement can be used to successfully increase hearing aid adherence in much younger children with and without developmental disabilities.

For the treatment of profound sensory neural hearing loss or deafness, surgical implantation of an electronic cochlear implant may be used. This

device electrically stimulates the cochlea via an electrode surgically implanted in the inner ear and a receiver implanted over the mastoid bone. These implants are combined with a behind-the-ear microphone, signal processor, and transmitter. Environmental sound is converted into electrical signals, which are transmitted to the receiver and then to the electrodes that have been surgically threaded through the cochlea. This stimulates nerve fibers on different locations along the cochlea. The cochlear implant cannot produce normal hearing, but it can improve detection of environmental and speech sound patterns and help with the development of speech production. It should be noted that improvement in functioning is variable and dependent, in part, on child and family motivation to participate in educational and rehabilitation services such as audiology and speech therapy. Motivating and maintaining the use of the external parts of the cochlear implant system and long-term participation in associated therapeutic activities can be facilitated by behavior management interventions.[8]

A recent study[22] assessed children's long-term use of their cochlear implant system and factors that appeared to influence adherence with the device. A sample of parents of 138 deaf children who had been implanted seven years earlier completed an annual usage questionnaire. Results indicated that after seven years 83% were wearing their system full-time, 12% most of the time, 2% some of the time, and 3% did not use their system. Factors associated with full-time use at seven-year follow-up were having been implanted at an early age (median of 4 years old), predominantly oral mode of communication (instead of sign language), mainstream educational placement, and availability of family and educational support. It was noted that in the nonusers, nonuse followed a period of fluctuating adherence. Thus, identification of such a pattern through regular monitoring may alert the implant team that these at-risk individuals should be referred for behavioral services to increase and maintain adherence.[22]

KEY CONCEPTS

- Severe sensory deficits in childhood may delay development of important skills such as walking, talking, and socialization.
- Early diagnosis and intervention can limit the impact of some sensory impairments.
- Understanding the nature and severity of sensory deficit allows for adjustment in educational strategies to emphasize the child's strengths and compensate for weaknesses.

- It can be quite difficult to test sensory abilities such as visual acuity accurately in individuals with IDD and limited verbal skills.
- Behavior analysis can facilitate sensory testing and help teach children and individuals with IDD to adhere to sensory interventions such as glasses and hearing aids.
- Sensory tests may require the child to cooperate with motion restriction and to tolerate the tactile stimulation produced by application of sensors, which is similar to the behavioral requirements for EEG and polysomnography.
- Behavioral intervention using differential positive reinforcement for wearing prostheses such as glasses or hearing aids and escape extinction of attempts to remove them has been effective in many cases.
- This training can be conducted in sessions of gradually increasing duration.
- A suggested technique is for the caregiver to place the glasses on the patient and immediately provide positive reinforcement (praise and access to preferred activities such as video entertainment).
- The caregiver should control the wearing time by counting aloud or setting a timer.
- Exposure can begin with only a few seconds and gradually increase as tolerance improves.
- The use of a timer with a bell or beeper alarm helps the individual learn that removal of the glasses or hearing aid is associated with the alarm (and passage of time) rather than contingent on his or her distress or disruptive behavior.

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Cooperation and Adherence with Breathing Treatments and Respiratory Assistance Technology

IN THIS CHAPTER

- This chapter presents intervention protocols and research that address cooperation, coping, and adherence with respiratory support procedures and technology such as positive airway pressure (PAP) devices, inhaled medication (nebulizer treatments), and tracheostomy care.
- The behavioral procedures presented are applicable to children and youth with or without intellectual and developmental disabilities (IDD).
- The behavioral strategies and procedures described can be generalized to other respiratory technologies that require cooperation with respiratory equipment and regimens.
- These methods can help children cooperate with pulmonary function testing, tolerate wearing a nasal cannula or oxygen mask, use a cough assist device, and cope with weaning from ventilator dependence.

9.1. PATIENT POPULATION AND TARGET PROBLEM(S)

Breathing disorders may occur in any child, adolescent, or adult, but several characteristics increase the risk that health-threatening breathing disorders will occur. Breathing disorders occur more frequently in individuals with IDD. Especially high risk groups include children with adenotonsillar

hypertrophy (enlarged adenoids and tonsils, which are gland-like tissues in the back of the nose and throat and are a nonessential part of the body's immune system), obesity, head and facial abnormalities, muscular dystrophy, cerebral palsy, and some types of genetic disorders such as Down and Prader-Willi syndromes.[1-2] Breathing problems negatively impact children's health, sleep, and behavior. They also can contribute to neurocognitive impairment and academic problems,[3] and if not effectively treated, they can result in life-threatening complications such as hypertrophy of the right heart ventricle. Adenotonsillectomy (surgically removing enlarged adenoids and tonsils) is the first treatment for most children with obstructive sleep apnea (OSA); however, some children continue to experience symptoms after surgery.[4] For the children who do not respond to surgery or for whom surgery would be too risky, alternative treatments are needed, and the most frequently recommended alternative to surgery is positive airway pressure therapy (PAP, CPAP, Bi-PAP).[5-6]

To cooperate with PAP, the child must breathe through a snug-fitting mask while sleeping. This can be particularly difficult for children with IDD and those with anxiety or behavior problems.[7] Such children often resist attempts by caregivers to put on the mask by turning their face away, using their hands to cover their face, or pushing away the mask. They often develop conditioned anxiety because the sight, sound, and sensations of PAP become associated with nonpreferred sensations from the mask, or with their own agitation from struggling to resist the mask.

9.2. ASSESSMENT PROCEDURES

By now the common assessment procedures that are recommended across medical situations should be familiar to the reader. These include observing and conducting a task analysis of the behavior required for cooperation and adherence and assessing the individual patient's preferred items and high-probability activities that may be used as reinforcers (conducting a stimulus preference or reinforcer assessment). An additional important step is conducting a functional assessment of the environmental and social variables that may motivate the patient to approach and cooperate with the medical technology and those that may motivate escape and avoidance behaviors that disrupt or prevent successful medical care. These assessment components are used to obtain important information for better understanding the child's behavior in the specific medical context. They are critical for planning a sequence of systematic exposures using mock

procedures or role playing to the distressing aspects of the medical protocol. These exposures are used for desensitization to the medical stimuli and counterconditioning of the patient's associated anxiety. At the same time, differential reinforcement is used to motivate the patient to approach stressful medical stimuli, learn specific coping behaviors, and use those coping responses at the appropriate time in the medical protocol.

9.3. APPROACHES TO HELP FAMILY CAREGIVERS AND HEALTH CARE PROVIDERS

Working with children with problems related to breathing can be difficult for all types of caregivers, even those who are expert pulmonologists or respiratory therapists. It can be challenging to determine if a child's distress is related to anxiety about potentially not being able to breathe, unfamiliar sensations caused by removing the respiratory equipment, actual respiratory insufficiency, problems related to low motivation to cooperate, or preexisting oppositional behavior problems. Obviously any behavioral assessment and intervention with children receiving respiratory support must be discussed and planned with the treating physicians. Any behavioral protocol should be approved by the medical team before it is implemented. Knowing that the physicians regard the intervention plan to be both medically indicated and safe can go a long way toward reassuring nonmedical caregivers.

The behavior therapist and family caregivers require education from the medical team about the respiratory technology and regimen. For example, understanding the importance of blood oxygen saturation level and the function of a pulse oximeter to measure saturation ("Sat") levels can be very helpful. Knowing that a child who appears highly anxious and distressed has normal oxygen saturation levels and has typical-appearing skin color (not pale, blue- or gray-tinged, or otherwise discolored) can help caregivers determine that the child is not in physical danger from lack of oxygen. Under such circumstances it may be appropriate to implement behavioral interventions that include blocking escape behavior, continuing exposure to nonpreferred stimulation, and prompting the use of coping strategies such as distraction or visual imagery. Providing behavioral intervention can also be much less frightening to the therapist or caregiver if it is provided with appropriate monitoring equipment and medical staff present. Some children may show changes in oxygen saturation levels because of hyperventilation or agitation associated with anxiety. Experienced medical or respiratory staff present can help ensure that

these changes are within an acceptable, nondangerous range. Therefore, our work in this area has involved close cooperation and, when indicated, co-treatment with medical, nursing, or respiratory staff present, especially in the early phases of assessment and trialing intervention strategies. A collaborative team effort that includes careful communication and collaboration among medical, behavioral, nursing, and respiratory caregivers is essential. If you are not in a setting where this level of collaboration is possible, it would be unwise to attempt to intervene with a child with a breathing disorder unless skilled private nursing or appropriately trained professional services can be arranged. Otherwise, the child should be referred to a therapist who practices in an interdisciplinary setting with the appropriate level of health care professional support and oversight.

9.4. INTERVENTION PROCEDURES

The intervention procedures described in this section were developed based on the literature reviewed in section 9.6. They were specifically designed to teach preschool-age children with developmental disabilities and OSA to cooperate with and adhere to a PAP regimen. PAP requires wearing a breathing mask and tolerating airflow into the mask with enough pressure to inflate the airway and prevent OSA during hours of sleep. Table 9.1 presents a task analysis developed for teaching children with OSA to cooperate with and adhere to a PAP regimen.[7]

In a protocol such as that developed for increasing cooperation and adherence with PAP,[8] counterconditioning is used to reduce the child's conditioned anxiety by gradual exposure to the medical supplies and equipment and the physical sensations he or she will experience. This exposure is conducted while the child is engaged in a distracting, pleasurable activity. The activities are selected to establish a relaxed pleasurable state that is incompatible with anxiety. Once the child is observed to relax and enjoy the activity, gradual exposure can be conducted by slowly moving the equipment closer to the child and slowly increasing the duration of contact with the equipment and its associated sensations (mask, smell of supplemental oxygen and plastic tubing, the sound of a PAP machine, air pressure in the nose, etc.).

As the child becomes less anxious and demonstrates fewer distress and escape/avoidance behaviors, cooperative behaviors can be differentially reinforced at each level of the task-analyzed medical care procedure until

TABLE 9.1 PAP Task Analysis

1. The child sits on the bed or stretcher.
2. The child cooperates with having the Bilevel PAP cap placed on the back of head.
3. The child lies in the supine position on the bed/stretcher.
4. The child remains supine and calm while the mask (not attached to the hose or cap) is placed in position on the face for five seconds.
5. The child remains supine and calm while the mask (not attached to the hose or cap) is placed in position on the face for 10 seconds.
6. The child remains supine and calm while the mask (not attached to the hose or cap) is placed in position on the face for one minute.
7. The child remains supine and calm while one side of the mask is attached to the cap. **Please note: Prior to next step, the mask will need to be connected to the tube and the tube will need to be connected to the machine.
8. The child remains supine and calm while the mask (attached to the hose and one side of the cap) is placed in position on the face and while the air is turned on for three seconds.
9. The child remains supine and calm while the mask (attached to the hose and one side of the cap) is placed in position on the face and while the air is turned on for five seconds.
10. The child remains supine and calm while the mask (attached to the hose and one side of the cap) is placed in position on the face and while the air is turned on for 10 seconds.
11. The child remains supine and calm while the mask (attached to the hose and one side of the cap) is placed in position on the face and while the air is turned on for one minute.
12. The child remains supine and calm while the mask is placed in position on the face and is connected to the cap on both sides.
13. The child remains supine and calm while the mask (attached to the hose and both sides of the cap) is placed in position on the face and while the air is turned on for one minute.
14. The child remains supine and calm while the mask (attached to the hose and both sides of the cap) is placed in position on the face and while the air is turned on for five minutes.
15. The child remains supine and calm while the mask (attached to the hose and both sides of the cap) is placed in position on the face and while the air is turned on for 10 minutes.
16. The child remains supine and calm while the mask (attached to the hose and both sides of the cap) is placed in position on the face and while the air is turned on for 15 minutes.

Source: Koontz, K.L., Slifer, K.J., Cataldo, M.D., & Marcus C.L. (2003). Improving pediatric compliance with positive airway pressure: The impact of behavior intervention. *Sleep*, *26* (8), 1010–1015. Reprinted with permission from The American Academy of Sleep Medicine.

the child can cooperate with each step. At the same time, escape extinction can be implemented by physically interrupting attempts to block, remove, or push away from the equipment. If the equipment (e.g., mask or supplemental oxygen tube) is successfully removed by the child, it must be

replaced immediately. Blocking escape behavior allows the child to experience the steps of the task while also having positive experiences through distraction, relaxation, and positive reinforcement. These treatment procedures must be presented at a rate that keeps the child's anxiety level at a minimum. This provides a safe, comfortable learning environment and the opportunity for success and positive reinforcement.

After the child is able to comfortably tolerate each step of the task analysis during behavioral therapy sessions, treatment effort can focus on increasing the duration of exposure to the equipment and related sensations. In terms of PAP adherence, the child needs to learn to fall asleep with a mask on and air pressure at the prescribed level. Parents and other caregivers should be helped to develop a consistent routine involving the medical technology. For example, with PAP the routine should begin about 30 minutes before bedtime. The routine should include calming, soothing activities and pair them with putting on and wearing the necessary medical equipment. For PAP therapy this culminates with putting on the PAP mask and lying down in bed to go to sleep. Direct caregiver training on the intervention procedures should be provided by modeling developmentally appropriate instructions, use of distraction, differential positive reinforcement, and escape extinction. Verbal and written instructions, therapist demonstrations, in vivo behavioral rehearsal with the child, and provision of corrective verbal feedback can be used to train the caregivers.

The behavioral strategies and procedures described above can be generalized to other respiratory support technologies that require cooperation with other respiratory support equipment and regimens. The author and colleagues have used these methods to help children cooperate with pulmonary function testing, tolerate wearing a nasal cannula or oxygen mask, use a cough assist device, and manage anxiety and behavioral distress when respiratory therapists are weaning them from ventilator dependence. In all of these applications, a behavioral therapist can establish patient cooperation and adherence with uncomfortable or anxiety-inducing pulmonary technology through a process that can be comfortable and even pleasurable for the child and caregivers if properly implemented and paced. Careful planning and implementation are required along with therapist and caregiver patience and a positive approach to teaching children new skills.

Use of direct observation measures to monitor child behavior is critical to conducting this type of behavioral therapy because it guides decision

making concerning when to challenge the child by increasing the difficulty of behavioral demands, when to reduce difficulty, and how to do so without reinforcing escape/avoidance behavior. With systematic performance data, the therapist and caregivers are able to perceive progress over time which sometimes is not apparent in any individual exposure trial or therapy session and to maintain their own optimism and motivation to help the child overcome emotional and behavioral impediments to medical care. As a result, children with and without IDD can benefit from health-sustaining pulmonary care in the least invasive manner (without sedation, restraint, or coercion). While clinical case data from our most recent applications await peer-reviewed journal publication, we have begun disseminating our results through peer-reviewed professional conference presentations.[9-10] A summary of the components of the behavior therapy protocol is presented below.

SUMMARY OF BEHAVIORAL PROCEDURES

1. Conduct a task analysis of the behavior required to adhere to the respiratory regimen.
2. Provide distraction from uncomfortable sensations using preferred activities.
3. Countercondition emotional arousal using preferred activities to induce relaxation.
4. Maintain the child's relaxed state with preferred activities, and then gradually expose her or him to the stimuli and sensations for each step in the task analysis.
5. Provide differential positive reinforcement by providing praise, stickers (as tokens), or controlled access to preferred activities contingent on cooperation with steps in the task analysis.
6. Provide negative reinforcement using contingent equipment (mask, nasal tube, etc.) removal by the therapist after a specified interval of child adherence.
7. Put escape/avoidance behavior on extinction by interrupting, blocking, or redirecting these behaviors and not allowing them to prevent respiratory equipment placement.
8. Provide a tangible prize or access to a favorite activity if the child was cooperative during the session or specified time period.

9.5. SPECIAL CONSIDERATIONS AND CHALLENGES

Providing the types of behavioral services described in this chapter can be especially challenging with toddlers and preschool-age children, as well as children and youth of any age who have severe IDD. Very young children and those with severe anxiety or behavior problems that occur across settings and not just during medical care require an extra level of behavioral training and experience on the part of the behavior therapist. The therapist must also be especially skilled, patient, and knowledgeable. For such children, the process of therapy can, at times, look disorganized and chaotic to an untrained observer due to the child's disruptive and dangerous behavior occurring in an attempt to escape nonpreferred or uncomfortable medical situations. In such cases, one must consider that learning may be slower, more training trials may be required, and more barriers to safety and success may arise. In these situations the availability of colleagues for backup and "extra hands" is critical. Sometimes two behavior therapists may be necessary, one to block and redirect disruptive, unsafe behavior, and one to implement the exposure, counterconditioning, and differential reinforcement-based procedures. Furthermore, behavioral intervention sessions may need to be brief and frequently repeated. Special environmental considerations may also be important, such as adequate facilities to keep an aggressive, self-injurious child safe while waiting out a tantrum when implementing an extinction-based procedure. Some children who are highly inattentive and escape motivated may learn more quickly if training is conducted in brief trials in one setting and then the child is allowed to leave the "'work' setting" for a contingent break in a "'play' setting" if he or she was cooperative during the training trial.

Children with autism or related disorders may be highly sensitive to changes in routine, tactile stimulation, unexpected noises, and the like. In all of these situations, it is not that the behavioral interventions described above cannot be successful, but that more time, patience, resources, planning, problem solving, and access to the patient and family will be necessary. Of course, if a respiratory support regimen is urgently needed and these extra behavioral and environmental resources are not available, behavioral intervention is not indicated. Finally, in especially difficult cases, referral to behavior analysts who work in a highly specialized setting that has intensive medical and behavioral resources will be needed. These

types of facilities are relatively rare but are most likely to be available at university-affiliated hospitals with special services for individuals with medical, developmental, and behavioral disorders. Such programs might be referred to as behavioral medicine programs and may be imbedded in departments of pediatrics or psychiatry at major medical institutions.

The take-home point of this section is to highlight the variability in difficulty and complexity of assisting children and youth who may present with breathing disorders and to urge the reader to be conscious of his or her capabilities, limitations, and resources before attempting to intervene to facilitate cooperation, coping, and adherence with respiratory care of individuals with special developmental, behavioral, or psychiatric needs.

9.6. SUPPORTING STUDIES

In an early behavior analysis study[11] four children with asthma were taught to use an intermittent positive pressure breathing (IPPB) apparatus to treat their asthma symptoms. The IPPB machine converted liquid bronchodilator medication into an inhalable form and delivered it under positive pressure to the children's airway. The IPPB device was equipped with a flow-sensitive valve that opened with slight inspiratory effort (inhaling). Flexible tubing, a small reservoir that holds the liquid medication, and a mouthpiece were all connected to the device. Three behavioral sequences that were required for correct use of the device were task analyzed and targeted for intervention:

1. sitting up straight, looking at an air pressure gauge on the front of the machine, and holding one's head at a 90 degree angle to the apparatus;
2. closing one's mouth around the mouthpiece, and avoiding both puffing cheeks and nose breathing; and
3. breathing with the diaphragm (diaphragmatic "belly" breathing) instead of intercostal muscles (muscles connected to the ribs).

These three behaviors needed to be synchronized into a sequence of responses that allowed the child to use the equipment correctly. The participating children were two boys and two girls ages 7–12 who were living at a residential treatment facility for children with chronic intractable asthma. These children failed to learn to use the IPPB device with repeated demonstrations and verbal instructions and therefore were referred for a behavioral training program. The intervention involved verbal instructions,

positive reinforcement, informational feedback, and sequential training on the required behavioral responses. Contingent positive reinforcement was provided in the form of tokens (play money) that were subsequently backed up with the opportunity to go on a shopping trip to purchase small gift items. The reinforcement contingency was introduced to train three responses: eye fixation, proper facial posturing, and diaphragmatic breathing. A multiple-baseline, single-subject, experimental design with replication across the three responses was used to systematically demonstrate intervention effects. These procedures were effective in teaching appropriate use of the IPPB apparatus. There was also evidence that when the children used the apparatus more correctly after training, they appeared to achieve more effective relief of asthma symptoms from their medication, and their need for follow-up medical treatment and medication was decreased. After behavioral intervention, more intense forms of treatment, hospitalization, and stronger medications were needed less often.

In a second experiment reported in the same publication,[11] nurses were instructed in the application of the behavioral techniques described above. When the trained nurses, in turn, implemented the intervention, they successfully taught two additional children to use the IPPB apparatus correctly. The data from these additional children further supported the positive effects of the intervention program and its generalization to children trained by staff members who were not themselves behavior analysts.

In a similar application of positive reinforcement contingencies,[12] a 2.5-year-old developmentally delayed boy was taught to cooperate with nebulized respiratory treatments. The child had a history of premature birth, developmental delay, severe hyaline membrane disease, persistent pulmonary hypertension, and emphysema. He had been hospitalized for three months before referral to the behavioral therapists for intervention.

The child had been prescribed 20 mg (2 cc) of Cromolyn (Intal) to be administered by nebulizer three to four times per day. For correct administration of this medication, the child was required to wear a respiratory mask over his nose and mouth during the treatments. Predictably for a child of this age, when the mask was placed on him, he cried, screamed, turned his head away from the mask, and pushed it away with his hands (typical escape/avoidance behavior). During a brief baseline assessment, the child turned his head from the mask during seven out of eight presentations. The average amount of time that he wore the mask was 5.26 seconds. For proper respiratory treatment, the child needed to wear the mask for 20 consecutive minutes, four times per day.

During behavioral intervention, two different treatments were implemented. The first involved positive reinforcement with squirts of soft ice cream from a syringe and praise contingent on wearing the mask for gradually increasing amounts of time. Problem behaviors such as head turns and blocking the mask with his hands were ignored. This treatment reduced the occurrence of head turning and blocking mask placement but did not increase the amount of time the mask was worn (average of 5.5 seconds).

The second treatment condition added escape extinction to teach the child that head turns and hand blocking would no longer allow him to escape the mask and treatments. When he attempted to turn his head, it was manually guided back to a midline position and held there for two seconds. Similarly, if he tried to grab or push away the mask, his hands were guided to his sides and held there for two seconds. As in the first treatment, differential positive reinforcement with soft ice cream was provided for cooperating for a specified interval without attempts to disrupt the mask by hand blocking or head turning. The required duration of wearing the mask began with a few seconds and was gradually increased as the child demonstrated success at the preceding duration. Using this combined escape extinction, differential positive reinforcement, and time fading approach, the child learned to wear the mask for the required 20 minutes, receiving ice cream reinforcement about every 4 minutes and rarely attempting to disrupt the mask. However, it is not known if lifting the mask enough to present the ice cream diminished at all the efficacy of the nebulizer treatments.

The effects of this intervention were maintained after discharge and at three-month follow-up when the child's mother administered the 20-minute nebulized treatments at home. The results of this case study demonstrated that escape or avoidance of the mask was probably a negative reinforcer. Head turning and hand blocking were most likely maintained by the associated naturally occurring negative reinforcement. This negative reinforcement had to be prevented before the positive reinforcement for wearing the mask could be effective. It is not known if the child would have learned to comply with the mask and treatments using only an escape extinction procedure, but the positive reinforcement procedure was easy to implement and made the learning a positive experience for the child. Practically speaking, there should never be a need to use escape extinction without an accompanying positive reinforcement contingency for cooperation and compliance. Furthermore, by gradually increasing the interval of compliance that is required for both positive and negative reinforcement to occur

(in this case contingent ice cream and removal of the mask by the nurse, respectively), the child was given the opportunity to learn the required behavior and to adapt to the nonpreferred stimulation involved in the treatment (sensation of the mask on his face, smell of medication, etc.). This case demonstrated an effective approach to treating medical noncompliance which was, overall, a positive learning experience for the child. Such positive learning experiences, rather than the aversive experience of being manually restrained for an unpleasant procedure, can make medical care much more humane for children with and without developmental disabilities.

In a published case study,[13] an 8-year-old boy with cystic fibrosis (CF), mental retardation, and autism was treated for noncompliance with essential respiratory treatments. He had been admitted to an inpatient behavioral unit for intensive treatment of aggressive behavior (i.e., hitting, biting). He also was noncompliant with the respiratory treatments in his CF medical regimen. The authors conducted a systematic behavioral assessment of variables that appeared to be maintaining his aggressive and noncompliant behaviors, and it was hypothesized that these behaviors were maintained by escape from nonpreferred activities and by adult attention to the problem behaviors.

An aerosol inhaler with a one-way detachable chamber was used for this boy's respiratory treatments, allowing him to inhale the medication by breathing normally, with the mask in place on his face for 20 seconds. His respiratory therapy regimen included two consecutive 20-second inhalations performed three times per day. The behavioral therapists recorded data on compliance and on the occurrence of aggression and avoidance (pushing away the mask or the therapist's hands, or turning his head away from the mask). Compliance was defined as allowing the mask to be held in position on his face for a specified period of time without any aggression or avoidance behavior.

In an initial baseline phase, the therapist attempted to hold the inhaler mask to the boy's face for 20 seconds on each of two trials. He received social praise contingent on compliance, but if he exhibited any aggression or avoidance behavior, the mask was immediately removed. Each trial was followed by a one-minute period during which the boy was required to stay in the session area but received no adult attention or access to activities.

Treatment to increase his regimen adherence involved providing adult praise and preferred items or activities contingent on compliance. Reinforcers

(candy, Matchbox cars, and Playskool figures) were selected based on the results of a systematic stimulus preference assessment.[14] Compliance resulted in access to all three preferred items for one minute. On the other hand, aggression or avoidance behavior terminated the trial, and as in baseline, each trial was followed by a one-minute period without adult attention or access to activities. In addition, a response-shaping procedure was used in which the interval of mask compliance required to obtain reinforcement was gradually increased by five seconds at a time until reaching the goal of 20 seconds. A mist without medication (placebo mist) was sprayed into the chamber when the mask was placed on the boy's face. The procedure was then conducted in various settings (medical treatment room, bedroom, and living area) by several different adults (nurses, direct care staff, and parents). The placebo mist was ultimately replaced with the actual medication, and gradually the amount of time for interacting with the reinforcing activities was decreased from 1 minute to 30 seconds. An A-B-A-B (also known as a reversal) single-subject experimental design was used to demonstrate the effects of the behavioral contingencies on mask compliance.

For the boy to be successful with his inhaled medication, he was required to cooperate with two 20-second inhalation treatments (40 seconds total) three times a day (120 seconds total per day). During pretreatment baseline, the mean duration of compliance was 13.8 seconds. The combination of shaping and reinforcement for compliance resulted in increased compliance and decreased aggression and avoidance. The amount of time the boy was required to be compliant in order to obtain reinforcement was gradually increased from 5 seconds to 20 seconds by the 24th treatment session.

During the final treatment phase, the mean duration of mask compliance was 37.2 seconds per administration, and during the last 26 sessions the treatment goal of 40 seconds of inhalation per administration was consistently achieved. In the 14 weeks after discharge the patient's compliance with his respiratory treatment averaged 97.7% of the targeted time.

According to the authors, the experimental design demonstrated that the reinforcement of compliance in this case study resulted in increased cooperation with respiratory treatment for CF. They noted that escape from the treatments was hypothesized to be the reinforcer that maintained aggression and avoidance behavior during this child's inhalation treatments. However, escape extinction was not directly included in the behavioral

treatment because the boy's caregivers were unable to safely implement escape extinction.

The authors speculated that two factors may have contributed to the effectiveness of behavioral treatment in this study. First, the time initially required to wear the mask was very brief. This necessarily increased the probability that the child would succeed in earning reinforcement from the first treatment trial. This probably further increased the likelihood that the child would comply with future demands for somewhat longer exposure intervals (a phenomenon termed *behavioral momentum*). Second, although the boy could always escape the respiratory treatments with disruptive behavior, this behavior resulted in the contingent loss of access to his reinforcing activities during the one-minute interval which otherwise would have been available to him. Functionally, this amounted to contingent time-out from positive reinforcement, which is a well-established behavioral deceleration (punishment) procedure often used in applied behavior analysis interventions. In any case, the results of this study suggest that sometimes compliance can be increased by using positive reinforcement procedures even when problem behavior continues to produce temporary escape from nonpreferred medical treatments.

Another aspect of pediatric pulmonary care to which behavior analysis has been applied is teaching self-suctioning to children with tracheostomies.[15] Tracheostomy involves making an incision into the trachea and inserting a tube below the larynx to establish and maintain an open airway. Children with airway obstruction due to an abnormal trachea may require tracheostomy for survival; after undergoing this procedure, children can typically live at home with their families, but they require regular suctioning to remove secretions from the tube and trachea to keep the airway clear. The investigators[15] examined the effectiveness of using dolls to teach young children with tracheostomies to self-administer a suctioning procedure. Four children between the ages of 5 and 8 who had tracheostomies were trained by practicing on a doll and then learning to perform the procedure on themselves.

A plastic doll with a tracheostomy tube inserted in its neck was used for practice. As with the many procedures described in this book, a task analysis of the procedure was developed. The task analysis for suctioning was based on available written descriptions and a series of direct observations. The skills that were identified and trained included gathering and assembling equipment, suctioning, and cleanup. The target steps included the following: (1) get ambu bag, (2) open catheter kit, (3) attach catheter to

machine, (4) pull wrapping off catheter, (5) test catheter in water, (6) open suctioning machine, (7) get paper cup and pour water, (8) open saline bullet, (9) place tissue on neck and turn on machine, (10) give three breaths by ambu bag, (11) administer saline to trach, (12) insert catheter into trach, (13) apply suction, (14) clean catheter in water, (15) dispose waste in trash, (16) clean machine tubing, (17) turn machine off, (18) close bottle of water, (19) put bottle away.

The participants were told that they could learn to suction their own tracheostomies and would first "help the doll to suction" before suctioning themselves. The children were told the steps to be performed, and the behavioral therapist demonstrated each target step with the doll while describing the actions performed. The children were then instructed to suction the doll's tracheostomy while describing what he or she was doing to the doll. The authors reported that the doll was held from a sitting position on the child's lap, facing forward, to simulate the orientation and positioning that would be experienced when self-suctioning. Correct responses resulted in immediate verbal praise. When an incorrect response occurred, the trainer provided descriptive verbal feedback and once again demonstrated the correct response with the doll. Then the child was instructed to perform the step again. This sequence was repeated as many times as necessary for the child to complete the step correctly without assistance.

A star chart system was used to reinforce participation in the training program, and at the end of each training session, the child was awarded a star for cooperative practice with the behavioral therapist. Stars were later traded for other tangible reinforcers. Training sessions were continued until 100% correct responding was demonstrated on the doll on all targeted steps for two consecutive training sessions.

Next the child was asked to suction his or her own tracheostomy, while a care provider with tracheostomy care certification (parent, teacher, or nurse) supervised his or her performance. The care provider interrupted incorrect, unsafe responses and helped the child, as needed, to perform the step safely. Training on self-administration consisted of instructions, child rehearsal, contingent descriptive praise, and corrective feedback until the child demonstrated 100% correct responding.

Results of this study were evaluated using a multiple-baseline design across subjects and components of the task analysis and indicated that all the children improved in their ability to self-suction after training was provided. These improvements were maintained by all the children at up

to six-week follow-up. Finally, the authors had the parents complete a follow-up satisfaction questionnaire and conducted a follow-up interview with the children. The results indicated high parent and child satisfaction with the training procedures and outcomes.

Based on their results, the authors regarded doll training to be a useful tool for teaching self-suctioning. They argued that the doll both helped motivate the child to participate in training and prevented exposing the child to dangerous or distressing conditions before she or he acquired the skills to self-suction safely.

As the authors emphasized in their discussion of the results, this training protocol must be individualized for each child depending on his or her specific suctioning needs, behavior, and developmental level. Most importantly, adult caregivers must carefully monitor the suctioning to ensure that it is performed correctly and to intervene if unsafe situations should arise.[15]

In a similar case study,[16] a 2-year-old girl with neurofibromatosis was taught to perform tracheostomy care on her doll. The child had undergone laser surgery to decrease the size of a tumor called a *neurofibroma* which was obstructing her airway. After her surgery, the child required a tracheostomy, and she was highly distressed and uncooperative with tracheostomy care. Initially she required restraint for this care to be completed. The medical team "performed a tracheostomy" on the child's favorite doll and taught her suctioning and tracheostomy care on her doll. The authors reported that after she became accustomed to performing these procedures on her doll, she was able to cooperate with her own care, and her compliance increased such that she no longer required restraint. While no systematic behavioral data were obtained in this case study, the results are consistent with and seem to add additional support to the results others have obtained.[15]

As mentioned earlier in this chapter, another pediatric pulmonary assistance device with which many children have difficultly cooperating is PAP. For over a decade the author of this book and his colleagues have been using applied behavior analysis techniques to teach pediatric patients to cooperate with and adhere to PAP therapy during hours of sleep for treatment of OSA and related disorders.[7-8] The first study[7] demonstrated the use of behavioral methods for increasing children's adherence with PAP. The outcome data from that study supported the utility of behavioral training for increasing PAP adherence.

That study included some children with IDD, and the results indicated that the children who achieved the greatest increases in mean hours per night of PAP adherence (e.g., >5.0 hours per night) were those reported to have higher levels of estimated cognitive functioning. This first study[7] was based on a nonexperimental analysis of retrospective clinic data. Therefore, a second study[8] was conducted using repeated-measures, single-participant experimental design. That study prospectively evaluated the effects of the behavioral training protocol on the PAP adherence of four preschool-age children with IDD, serious health impairments, and behavioral distress in response to PAP.

The percentage of steps in the PAP task analysis which were completed during each observed PAP administration was recorded as a measure of child compliance. PAP adherence was also measured by recording the number of hours per 24-hour period that the child wore the PAP equipment. This study tested whether or not the percentage of steps completed and the number of hours of PAP adherence would significantly increase as a result of the behavioral intervention.

The four children were identified for behavioral intervention because of their severe distress reactions to the PAP mask and airflow during initial attempts to conduct breathing tests during sleep (polysomnography) or to initiate PAP therapy. Their severe behavioral distress and attempts to escape the mask and equipment were keeping them from receiving the important benefits of PAP. Behavioral assessment and intervention were conducted using behavioral rehearsal sessions during which the PAP equipment, mask, and airflow were presented one step at a time according to the sequence outlined in our previously published PAP task analysis.[7] The four children in this study were 3–5 years old, had developmental delays, and had one or more serious health impairments (e.g., obesity, heart problems, diabetes, asthma, lung abnormalities, prior surgery for tumor removal). In all four cases initial clinical observation indicated that the children did not reliably comply with parental instructions. Three of them had been admitted to a rehabilitation hospital for medical and behavioral intervention, and the fourth one received in-home nursing services for medical monitoring and care.

Before beginning the behavioral intervention, each child's mask and equipment were assessed by a nurse or respiratory therapist and the behavior therapist to determine if the child's mask fit properly. If there were pressure marks on the skin or air leaks into the eyes causing discomfort to

the child, modifications were made. For example, a petite-size "gel mask," a spacer, a soft cap, heated humidification, and a delayed pressure "ramp up" function were used to improve the child's physical comfort with the mask and apparatus.

Each child was observed during one or two PAP placement attempts. Initial adherence data were recorded along with information about the child's favorite activities (snacks, bubbles, video games, movies, singing, and small prizes), which would be used to relax, distract, and motivate the child.

Three behavioral techniques were used: counterconditioning, escape extinction, and shaping cooperative behavior using differential reinforcement. A prospective, repeated-measure, nonconcurrent, multiple-baseline experimental design was employed to display and evaluate the data across the four children.

The behavioral protocol was effective for desensitizing these four preschool-age children with developmental delay, behavior problems, and serious health conditions to PAP. Prior to behavioral training, none of the children were consistently wearing the PAP equipment. After behavior therapy and caregiver training, all of the children successfully tolerated PAP and increased their hours of use to a level consistent with that required for health benefits.[8]

This study provided evidence of the benefits of our multicomponent behavioral intervention for increasing adherence and decreasing distress during PAP regimen in preschool-age children, if a consistent behavioral training protocol is implemented.

Taken in combination, the studies described above provide empirical support for the usefulness of behavior analysis and therapy in decreasing anxiety, behavioral distress, and escape/avoidance behavior while systematically increasing cooperation and regimen adherence in children with breathing disorders. The combination of task analysis, distraction, graduated exposure, counterconditioning, shaping compliance through differential reinforcement, and escape extinction appears to provide a versatile set of therapy techniques that are effective for increasing child cooperation with and adherence to a variety of pulmonary treatments.

9.7. CASE EXAMPLE

This case involved a 7-year-old, typically developing child who had suffered a spinal cord injury, lost the function of her arms and legs, and had been

ventilator dependent since her injury. The physicians and respiratory therapist felt that she had the ability to breathe on her own and to be "weaned" from the ventilator. Therefore, they began attempting to wean her from the ventilator by making sure that her blood was well oxygenated in advance (her Sat levels were appropriately high on the pulse oximeter) and then removing her from the ventilator by disconnecting the tubing and temporarily capping her tracheostomy tube. These test trials ("vent sprints") were attempted for up to one hour in duration. When these attempts were made, the child became distressed, cried, made verbal refusal responses, and appeared to hyperventilate. As these trials progressed, she became increasingly more distressed, and the sessions were discontinued in response to her increasing distress. After these trials had failed, our pediatric psychology team was consulted to attempt to decrease the child's distress, which was occurring both before (anticipatory distress/anxiety) and during the "vent sprints." We hypothesized that the prior weaning attempts had most likely increased the child's distress through negative reinforcement due to contingent escape from uncomfortable sensations in response to increasing levels of distress behavior. Therefore, we set up a systematic exposure therapy protocol that began with brief intervals off of the ventilator and gradually increased in duration across exposure trials. Most importantly, the trials were time based rather than response dependent. For each trial, a timer was set and the trial ended when the timer alarm signaled the end of the trial interval and the ventilator tube was reconnected. The end of the trial was independent of whether the child was displaying increasing or decreasing distress. The therapist also provided child-preferred activities during the vent sprint trials to distract the child from focusing all her attention on any uncomfortable sensations she might experience while adjusting to the increased effort of breathing on her own. Verbal reinforcement was provided during and at the end of each trial, and the child was allowed to set the next time goal, as long as it was greater than the previous trial (even if only minimally greater).

Over time, the duration increased and the vent sprint trials were conducted first in the child's hospital room and later in other settings such as a group playroom in order to generalize results to other environments. For each trial data were recorded on the number of minutes the child was off of the ventilator, and the respiratory therapist rated the child's level of distress using a four-point scale ranging from 0 = no distress to 3 = high verbal and physical distress (crying, hyperventilating, vomiting). The data

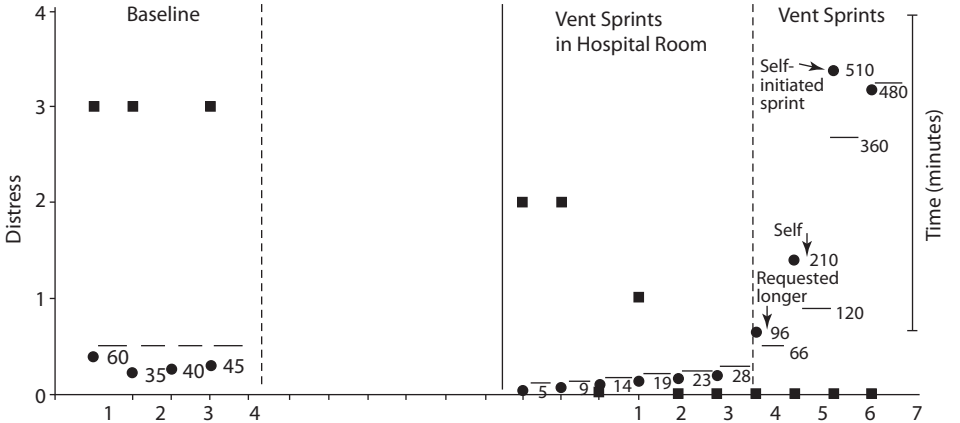

Figure 9.1 Level of therapist-rated child distress (*squares*) and duration of time off of respiratory ventilator in minutes (*circles*) across baseline and behavioral intervention conditions for a 7-year-old, quadriplegic girl during "vent sprints." The short horizontal lines indicate the time goal set for each session. The data markers (*circles*) and numbers next to them show the observed duration of each trial off of the ventilator.

Source: Herman, L., Maynard, C., Fletcher, A., Beck, M., Slifer, K.J., & Amari, A. (2007). Behavioral interventions to decrease anxiety during uncomfortable pulmonary treatments. Society for Pediatric Psychology, APA Division 54, National Conference on Child Health Psychology, San Francisco, CA.

across baseline and behavioral treatment sessions are displayed in figure 9.1. The data indicate that during baseline, the child displayed high levels of distress and was unable to cope with the expected vent sprint duration. After a break of several days with no attempts at vent sprints, the behavioral intervention described above was introduced. With the introduction of behavioral treatment, the respiratory therapist's ratings of the child's distress level decreased, and after the sixth trial, the ratings remained at zero. The child was successful at coping with the gradually increasing time off of the ventilator. As intervention progressed, she began to request more time off of the vent after she had already reached the time goal she had set for the trial.

This case illustrates the strength and generality of behavior analysis and therapy for increasing coping and adherence with medical treatment in a child who required a challenging and distressing pulmonary treatment regimen for optimal health and physical functioning. This case also demonstrates the power of systematic exposure therapy with gradual increases over time and time-dependent (rather than response-contingent) termination rules to counter a history of negatively reinforced escape behavior. Differential social reinforcement for tolerance of and coping with the distressing stimulation involved in medical care was another important part of the behavioral intervention package. The intervention also allowed the child a measure of control and self-determination, which likely helped to decrease her level of anxiety and distress, especially during the initial trials. Given that this was a multicomponent intervention package and we used only an A-B (baseline-treatment) single-participant design, it is not possible to determine the relative contributions of graded exposure, time-contingent escape, differential positive social reinforcement, and self-determination of exposure goals. Such a determination will require additional research with multiple participants and carefully planned experimental designs. Nonetheless, this case adds incremental evidence to support the utility of behavior analysis and therapy methods for altering aspects of the interface between patient, medical staff, and medical equipment to support child cooperation, coping, and adherence with challenging aspects of specialized respiratory care.

KEY CONCEPTS

- Breathing disorders occur more frequently in individuals with IDD, especially those with enlarged adenoids and tonsils,

obesity, head or facial abnormalities, muscular dystrophy, cerebral palsy, and some types of genetic disorders such as Down syndrome.

- Breathing problems negatively impact children's health, sleep, and behavior; can contribute to thinking impairments and learning problems; and, if not effectively treated, can result in life-threatening health complications.
- Helpful assessment strategies include conducting a task analysis of the behavior required for cooperation, determining the child's reinforcer preferences, and conducting a functional assessment of the environmental and social variables that may be motivating escape/avoidance versus approach and cooperation.
- Any behavioral assessment and intervention with children receiving respiratory support must be discussed and planned with the treating physicians. Any behavioral protocol should be approved by the medical team before it is implemented.
- Using direct observation measures to monitor child behavior guides decision making concerning when to challenge the child by increasing the difficulty of behavioral demands, when to reduce difficulty, and how to do so without reinforcing escape/avoidance behavior.
- Behavioral interventions to increase cooperation and adherence with breathing treatments and respiratory regimens include (1) using preferred activities to distract the child's attention from uncomfortable sensations, countercondition emotional arousal, and induce relaxation; (2) gradually exposing the child to the stimuli and sensations for each step in the medical regimen; (3) providing differential positive reinforcement with praise, tokens, or controlled access to preferred activities contingent on cooperation with steps in the regimen; (4) providing negative reinforcement by contingent removal of the equipment (mask, nasal tube, etc.) by the therapist after a specified interval of child adherence; (5) putting escape/avoidance behavior on extinction by interrupting, blocking, or redirecting these behaviors and not allowing them to prevent respiratory equipment placement; and (6) providing a tangible prize or access to a favorite activity if the child was cooperative during the session or specified period of wearing the equipment.

- To successfully implement these procedures with children with more severe developmental disabilities, psychiatric disorders, or severe behavior problems, more time, patience, resources, planning, problem solving, and access to the patient and family will be necessary.

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Teaching Children to Swallow Pills and Capsules

IN THIS CHAPTER

- This chapter discusses oral medication refusal in children and youth, which can be a serious impediment to medical care.
- Some of the variables that contribute to medication nonadherence are considered, such as the unpleasant taste of some liquid medications and pills, unpleasant side effects, the size and shape of pills and capsules, the child's oral motor skills, anxiety about choking, and the level of parental supervision and encouragement.
- Training procedures for pill swallowing from the published literature and recent clinical experience are presented.
- Stimulus-fading and response-shaping techniques for effectively teaching children to swallow pills and capsules of various sizes are described and explained here.
- Supporting behavior analysis research and related studies from the literature are reviewed.

10.1. PATIENT POPULATION AND TARGET PROBLEM(S)

For the purposes of this chapter, *compliance* and *cooperation* will be used interchangeably to discuss the immediate behavior required for ingesting medication when presented. The term *adherence* will be used to refer to reliably taking medication over time according to the prescribed dosage and schedule once the child has demonstrated the ability to accept and swallow it when presented.

People of all ages can have difficulty with taking medication and adhering to a prescribed medication schedule. This difficulty can occur for a host of reasons that will be discussed throughout this chapter. Adults may have difficulty appreciating the purpose of the medication or the importance of taking medicine at the right time, in the right amount, and either taking the entire course of medication (taking all of the prescribed antibiotics) or taking medicine for maintenance of wellness (antidepressants for a person with a history of major depression). Many people fail to understand that one cannot necessarily discontinue a medication because symptoms are no longer occurring. People of all ages can have thinking and memory problems that may interfere with medication adherence. This is even more likely in individuals with a history of injury or illness affecting the brain and in those with intellectual and developmental disabilities (IDD).

Many children may have difficulty accepting medication of some type, especially during early childhood. Fortunately, many medications routinely prescribed for children are flavored and sweetened to appeal to children (favorites often include bubble gum, grape, cherry, orange, and strawberry). When medication is not already flavored for children, many pharmacies are able to prepare medicine for children by adding flavoring. Some pharmacies carry a brand of special flavoring for liquid medication called FLAVORx (FLAVORx, Inc., 9475 Gerwig Lane, Columbia, MD 21046; 800-884-5771; www.flavorx.com; info2@flavorx.com) that physicians or parents can request, provided that the flavoring contents are compatible with the medication, which is usually not a problem.

Another alternative is for parents, with physician and pharmacist approval, to flavor the medication themselves. This can be done with liquid medication or with pills that are crushed and then mixed with a flavoring liquid, syrup, or thickened liquid. Some capsules also can be opened and mixed with flavoring in the same way, but some may involve specially formulated granules that produce a time-release mechanism. One must always check with the prescribing physician and dispensing pharmacist for clearance to open and mix capsules in this way. Inexpensive pill cutters and crushers can be bought at most pharmacies and many supermarkets. For physician-approved self-flavoring, cherry, chocolate, strawberry, and grenadine syrups are readily available at supermarkets. Similarly, depending on the patient's taste preferences, medications can be mixed in pudding, yogurt, milk, milkshakes, apple sauce, or smoothies of a variety of flavors.

One problem with flavoring medication with any of the methods mentioned above is that the unpleasant (sometimes foul) taste of some medica-

tions cannot be effectively disguised. In these cases the person may develop taste avoidance for both the medication and the flavoring, that is, a favorite flavor or food may become nonpreferred or even nauseating because it has been paired with the nauseating medication. For this reason the reader is cautioned not to mix medication in a patient's favorite food because under some circumstances the patient may stop eating it or similarly tasting foods, or may start avoiding food altogether. This is an especially difficult problem in medical patients who may have poor appetite as a part of their illness or recovery from injury.

Children with chronic medical conditions may grow up from infancy taking liquid medication and may never have difficulty accepting it. On the other hand, children with chronic conditions requiring long-term medication may develop medication compliance problems for a variety of reasons. Some of these may involve the need to transition from liquid to pills or capsules. Developmental factors come into play. Many children and even teens and adults may have significant difficulty learning to swallow pills or capsules. This may be because of anxiety about choking, delayed or incomplete development of the oral motor skills required for pill/capsule swallowing, or the individual's inaccurate beliefs about his or her anatomy or ability.

People of all ages can have difficulty with unpleasant side effects of medication, and if the medication, whether in liquid, pill, or capsule form, has an unpleasant taste, texture, or smell, it may induce gagging, retching, nausea, or vomiting. Under these circumstances, patients may quickly develop a conditioned response such that even the sight or smell of the medication induces these unpleasant physical responses.

Learning to swallow pills or capsules is very often the solution to medication noncompliance. If necessary, it is possible (though challenging) to insert bad-tasking pills into empty gelatin capsules by either inserting the pill in a larger capsule or crushing the pill and inserting the powder into the gelatin capsule. With physician approval, some pharmacies may perform this service, or for the adventuresome patient or parent, this could be done at home by hand (obviously this tedious, time-consuming approach would be a last resort).

Finally, for very young children and some individuals with IDD, if pill or capsule swallowing cannot be mastered or conditioned nausea and vomiting cannot be counterconditioned or overcome in some other way, medication can be administered through a feeding tube or an intravenous tube (IV). These too are last-resort approaches but may be necessary in some

circumstances. The decision to use a feeding tube or IV is, of course, a medical decision to be made by the treating physician in consultation with the patient and/or family. The advantage of a young child having a gastric tube through which medication can be administered is that it decreases the stressful urgency of trying to get the child to accept the medication by mouth. In these cases, families may still seek the assistance of a behavior therapist to help teach the child to accept medication orally, but this can be done at a more leisurely pace that is not so stressful for the child or family. This can be done using some form of juice, syrup, or candy "pills" as the mock medication to administer during practice sessions.

10.2. ASSESSMENT PROCEDURES

Assessing the variables that are maintaining medication avoidance, noncompliance, or nonadherence can be straightforward or complex. Assessment begins with obtaining a history of the patient's health status and past experiences with medication. Most importantly, does the child have any medical condition that impairs his or her ability to swallow? For example, children with a history of cerebral palsy, brain injury, feeding disorder, or acid reflux may have physical difficulty with swallowing and will need to be monitored and managed appropriately when attempting to increase their medication compliance. If the child is known to have oral motor coordination or swallowing difficulties, has she had a medical swallow study and been cleared for regular food textures and thin liquids? Are there physician-prescribed restrictions on what the child can eat and drink which must be considered? Has the child ever taken oral medication before? What about pills or capsules? What size pills or capsules can she swallow, if any? Has she choked on medicine or experienced nausea, vomiting, or other unpleasant physical reactions to medication? Is he cooperative with some types and flavors of medication but not others? Does he say or demonstrate through his behavior (pushes away, turns his head, gags, spits, etc.) that he dislikes its taste? Does she say that she is afraid or show anxious behavior when medication is discussed or is visible? Has anyone ever tried to administer medication by coercion or force, which may have been an emotionally traumatic experience for the child? This information can be obtained through a combination of interviewing the child and family and direct observation of attempted medication administrations (this can be done either with medication that has already been prescribed and obtained or by using physician-approved flavored liquid or candy pills).

As discussed in earlier chapters, it is always important to assess the generalized compliance of a child or an adult with IDD. If he will not follow routine caregiver instructions (come here, sit down, put your toy away, etc.), it is unlikely that he will cooperate with medication administration. Also, it is important to do an assessment of the individual's preferred activities and items that could be used to reinforce general compliance, medication acceptance, and swallowing.

Finally, it is important to consider the antecedent (environmental) conditions that are at hand when the medication is being given. A child who is running away or hiding under a table is unlikely to comply with medication administration. The child should be seated in a high chair, booster chair, or stroller that helps keep him in a seated, upright position. Although there may be exceptions for seriously ill individuals, generally one should not attempt to give medication to someone who is lying down and especially not when they are sleeping. Whenever possible, medication should be given in the same place at the same time and under the same conditions every time it is given. If medication compliance is a problem and involves the child becoming distressed, it would be ideal to give the medication in a special location that is only used for medication administration. Then, after the child accepts and swallows the medication, he or she can be allowed to leave the special location. Preferred activities should be available in that location to provide to the child contingent on medication acceptance and swallowing. Preferably, the toys, activities, or preferred snacks or liquids used to reinforce medication acceptance and swallowing should be kept apart for exclusive use during medication administration. In some cases controlled preferred activities can be used to distract the child during some aspects of the medication administration routine. The timing of stimulus presentation during medication routines needs to be carefully orchestrated, especially when the child is first learning to comply with his or her medication regimen.

Approaches to Help Family Caregivers and Health Care Providers

Sometimes solving a medication compliance problem can be as simple as structuring the administration routine to include proper seating, appropriate verbal instructions, and provision of praise and a sip of preferred liquid to "chase" the medication and reinforce compliance ("a spoon full of sugar helps the medicine go down"). However, most cases of medication noncompliance which come to the attention of pediatric psychologists

and behavior therapists are more complicated. The problem almost always can be solved with behavioral intervention, but that intervention may take time and look messy before the child learns to comply, especially if the child has generalized noncompliance problems and a history of escape/avoidance behavior being negatively reinforced by caregivers "giving in" and withdrawing behavioral demands when the child becomes distressed. In these cases, escape/avoidance behavior can appear quite dramatic, with escalating behavioral distress when escape extinction–based procedures are employed. This may involve crying, whining, screaming, head turning, pushing away, hitting, dribbling, spitting, gagging, retching, and vomiting. This can be difficult for professionals to observe and endure and may leave family caregivers shouting or in tears. This can create the twin demons of fear of traumatizing or harming the child and fear of failing to get necessary medication into the child. The emotional distress that this creates in caregivers is a major impediment to follow-through and success. This can be much worse when there is any belief that the medication is optional. When medication is life sustaining, such as insulin for children with type 1 diabetes, caregivers seem to be more able to muster the resolve necessary to tolerate temporary child distress. They don't like the idea of giving injections to their child, but they recognize that the alternative is unacceptable.

When medication is important, but nonadherence results in no obvious negative health consequences for the child, caregivers seem to be at greater risk of reinforcing escape/avoidance behavior by discontinuing their attempts to give the medication. In these situations, it can sometimes be helpful to remind caregivers that no one is able to go through life without experiencing some discomfort and distress, and that we do a child (even one with a chronic illness) no great service if we try to protect him or her from anything that might be distressing. As in all aspects of their lives, children need to experience distress in doses that challenge their ability to cope but do not overwhelm them with unpredictable and uncontrollable stressors. They must learn to experience limits on their behavior and to learn to regulate their behavior in the face of nonpreferred situations, discomfort, and disappointment. If properly orchestrated, a medication administration can be relatively brief and the distress eventually reduced to a minimum, if not eliminated. Some medication compliance interventions can be intense in the early stages, but with consistency and resolve, they typically are successful in a matter of days. Once the stressor is resolved (the liquid medication has been swallowed) and the child is redirected to

preferred activities and reinforced for his coping, he is likely to recover quickly from his distress. Reminding caregivers to consider the trade-off between brief, time-limited distress and longer-term health benefits can be reassuring and help sustain their resolve when the going gets tough.

Finally, in some situations the medication is so important and the behavior problems so ingrained that the physicians may decide that a feeding tube or IV medication is warranted. As suggested above, the advantage of these situations is that they can solve the immediate urgency and allow behavioral intervention to proceed at a comfortable pace using simulated liquid medication or placebo pills/capsules (sugar pills, small candies, gelatin capsules filled with corn starch). In this way the child's immediate medical needs are addressed while she or he works at a comfortable pace on acquiring an important life skill. Medication ingestion skills such as pill swallowing are certainly worth the effort for children with chronic health conditions that will require medication over the course of a lifetime.

10.3. INTERVENTION PROCEDURES

There have been relatively few published studies about behavioral approaches to teaching children and youth to swallow pills and capsules. Those studies are reviewed in some detail in section 10.6. Stimulus fading and response shaping using differential positive reinforcement have been the fundamental techniques used to teach children to swallow pills and capsules of various sizes. In most studies the pill-swallowing training protocol has been conducted during practice sessions with practice "pills" of increasing size to implement the stimulus-fading and response-shaping procedures across a hierarchy of practice pills. Figure 10.1 illustrates such a hierarchy.[1]

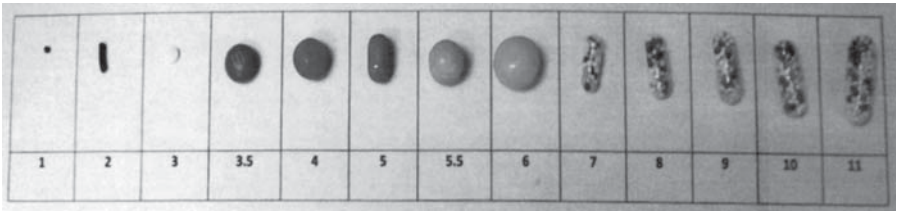

Figure 10.1 Mock pills of increasing sizes illustrating systematic stimulus fading. Reproduced with permission from Marocco, L., Bierenbaum, M., Spencer, K., et al. (2011). Pediatric pill swallowing: One size doesn't fit all. American Psychological Association, Division 54, National Conference on Child Health Psychology, San Antonio, TX.

Step-by-step instructions for the pill-swallowing training procedures from a study in which the author of this book and colleagues collaborated are listed in table 10.1.[2]

The results from one participant in another study[3] (discussed in section 10.6) were also presented in a book chapter on behavioral consultation in hospital settings.[4] Figure 10.2, reproduced from that chapter, illustrates graphically the process of using practice pills/capsules and systematic stimulus fading to establish a child's ability to swallow prescribed pills/capsules. This graph displays the percentage of practice pills or capsules swallowed by the child on the vertical axis and sessions on the horizontal axis. The filled black circles indicate the use of actual prescribed pills or capsules, and the open circles indicate the use of practice pills or capsules. Changes in the size of the practice pills are indicated by the relative size of the data markers. This figure illustrates the gradual process involved in training, as well as the relative efficiency of training. It also presents a model for how data can be graphed to document the effects of training with an individual child across sessions.

The behavior principles, procedures, and objectives are essentially the same when liquid medication adherence is the objective. The primary difference is the form of the medication stimulus. Training can be conducted with mock medication (flavored syrup, juice, etc.), and the same discrete trial format can be used. If approved by the prescribing physician, liquid medication can often be made more palatable by mixing it with a preferred flavor; however, one should not go on a protracted search for the "perfect" flavoring to mask the taste of the medication. There often is no such perfect solution, and ultimately children must learn to swallow medication when presented by an adult even though it may have a nonpreferred or aversive taste. Offering a preferred liquid or food as a "chaser" immediately after the medication is swallowed can be helpful with improving any type of oral medication acceptance. Various types of syrups and liquids can be used for mixing medications (with physician approval), such as cherry, grenadine, chocolate, strawberry, or maple syrups; orange or apple juice; and fruit punch. Using the mock liquid medicine, compliance trials are conducted until the child will reliably accept and swallow the mock medication when presented. Then the liquid medication is presented in the same manner. If the physician has approved the mixing of the actual medi-

TABLE 10.1 Step-by-Step Instructions for Pill-Swallowing Training Procedure in Young Children with Autistic Disorder

1. Obtain information regarding any food and drink preferences, aversions, and/or allergies in the child.
2. Obtain information regarding potential reinforcers for the child.
3. At the beginning of the pill-swallowing training procedure (before progressing to the presentation of pills), as well as at the beginning of each session, assess the child's ability to perform the following prerequisite gross motor behaviors and four specific, basic oral motor responses, when prompted. If the child is not able to perform these prerequisites, teach the skills individually to the child through demonstration, verbal and manual prompting, and differential reinforcement with contingent praise and/or tangible reinforcement (sticker, bite of preferred food, etc.).
   3a. Specific gross motor behaviors:
      - Come here
      - Sit down
      - Hand me the toy
   3b. Specific oral motor responses:
      - Open your mouth
      - Say "ahh"
      - Stick out your tongue
      - Swallow
4. For the pill-swallowing behavioral rehearsal sessions, children practice swallowing cake decorations of gradually increasing size (candy sprinkles, candy dots, etc.). To establish the size of the "practice pill" to be used to initiate the pill-swallowing training sessions, first assess the size of the practice pill the child can tolerate by presenting sequential sizes, one at a time, starting with the smallest-size cake decoration (e.g., candy sprinkles).
5. Begin the pill-swallowing training session by using the largest size of the practice pill the child can swallow without distress or gagging.
6. Place the practice pill on the child's tongue with one hand and immediately offer the child's preferred drink with the other hand.
7. If the child swallows the practice pill, praise the child's success ("You did it!") and provide a tangible reinforcer, such as a sticker or a bite of preferred food. Ask the child to pick his or her own sticker or snack food in order to keep the child motivated.
8. If the child does not swallow the practice pill, say in a neutral tone, "No chew," "No spitting," or another appropriate short and clear prompt based on the child's behavior and offer the same-size practice pill again.
9. Plan a break after three to five trials or earlier, based on clinical judgment and/or the child's response to the behavioral training (e.g., compliance, success, ability to attend, or level of activity, frustration, or anxiety).
10. Establish a stimulus-fading criterion, requiring two consecutive successful swallows before introducing the next-size practice pill, which should be noticeably, but only slightly, larger.
11. Continue to increase the size of the practice pill until the child successfully swallows a practice pill that is equal to, or larger than, the size of the pill the child is required to take.

(*Continued*)

TABLE 10.1 (*Continued*)

12. At the end of each visit, invite the caregiver into the room and demonstrate the pill-administration procedure for the caregiver, using the largest size of the practice pill the child has swallowed.
13. Repeat until the child demonstrates two consecutive successful swallows in front of the caregiver with the practice pill being offered by the therapist.
14. Next, prompt the caregiver to issue the following sequence of commands to the child and to present the same-size practice pill as offered by the therapist. In addition to the prompting, the therapist should provide performance feedback to the caregiver throughout the session.
    - Come here
    - Sit down
    - Open your mouth
    - Say "ahh"
    - Stick out your tongue
    - Caregiver to place the pill on the child's tongue with one hand
    - Caregiver to offer the child's preferred beverage with the other hand and prompt the child to swallow
15. Prompt the caregiver to offer differential reinforcement of *attempts or successful swallows* with contingent praise and tangible reinforcement.
16. The caregiver should continue to rehearse under the therapist's guidance until the child successfully swallows the practice pill offered by the caregiver on two consecutive trials.
17. Ask the caregiver to practice daily with the largest practice pill that the child has swallowed successfully for the caregiver during the clinic visit.
18. Encourage the caregiver to use identical or similar reinforcers as employed in the clinic session. Give them stickers to use at home and encourage them to use similar toys or snacks as tangible reinforcers.
19. Advise the caregiver not to independently advance pill size or to experiment with protocol modifications at home, but to contact the therapist if the child experiences any difficulties during the home practice so that negative experience is minimized.

Source: Ghuman, J.K., Cataldo, M.D., Beck, M.H., & Slifer, K.J. (2004). Behavioral training for pill swallowing difficulties in young children with autistic disorder. *Journal of Child and Adolescent Psychopharmacology*, *15*, 601–611. Reprinted with permission from Mary Ann Liebert, Inc.

cine with the flavored liquid, then the amount of flavoring can be gradually reduced over time to either eliminate the need for the flavoring or reduce it to the minimum amount necessary to maintain compliance. As mentioned earlier in this chapter, commercially available flavoring for liquid medication does exist (FLAVORx) and can be requested at many major pharmacies.

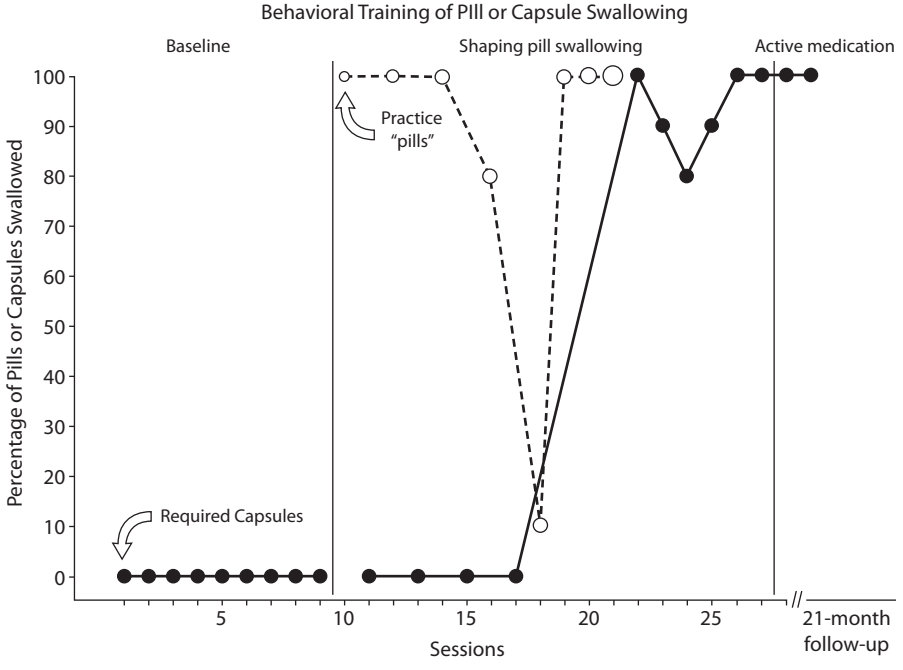

Figure 10.2 The percentage of practice pills is indicated on the vertical axis and sessions on the horizontal axis. The filled circles indicate the use of actual prescribed pills or capsules, and the open circles indicate the use of practice pills or capsules. Changes in the size of the practice pills are indicated by the relative size of the data markers. *Source*: Slifer, K.J., Cataldo, M.D., Babbitt, R., & Cataldo, M.F. (1993). Behavioral consultation in hospital settings. In J. Zinns, T. Kratochwill, & S. Elliot (eds.), *Handbook of Consultation Services for Children: Applications in Educational and Clinical Settings* (pp. 291–304). San Francisco: Jossey-Bass. Reprinted with permission from John Wiley & Sons.

10.4. SPECIAL CONSIDERATIONS AND CHALLENGES

Most of this chapter focuses on the problem of medication compliance—getting an uncooperative, unmotivated, or anxious child to accept and swallow liquid medication, pills, or capsules. Getting a child to do so on a routine basis is another matter altogether, which is referred to by health psychologists as "medication adherence." Considerable research has been conducted on the variables that impact medication adherence in people with various medical diagnoses, especially adult medical patients.[5] The

reader is directed to that literature and to the substantial literature on pediatric medical regimen adherence.[6–8] However, for the purposes of this chapter, it is important to note that there are many barriers to consistent medication adherence for children and families, including (1) general child compliance problems; (2) unpleasant side effects of medication; (3) difficulties in filling medication prescriptions due to lack of financial resources or reliable transportation; (4) inadequate parental supervision because of work schedules or misguided developmental expectations; (5) lack of understanding of the consequences of nonadherence, which may not be immediately apparent; (6) children's motivation to be "normal" and not seem different from peers; (7) child and/or parent IDD, depression, or other mental health problems; (8) adolescent and/or parental substance abuse; and (9) family dysfunction and conflict. Any one or combination of these factors can have powerful effects on the medication adherence of a child or adolescent.

10.5. SUPPORTING STUDIES

Before the 1980s, few studies were conducted to address the causes of oral medication noncompliance. The challenge of teaching children to swallow pills required for their successful health care was rarely mentioned in the behavioral or psychological literature. Before 1980, one paper reported using behavioral interventions to successfully improve the pill swallowing of two girls ages 18 and 24 months.[9] Both of these children had a life-threatening illness (nephritic syndrome, leukemia). Some of the techniques that were used by these authors would not be considered ethical today except under the direst of circumstances, and only with legal guardian informed consent and institutional ethics committee review and approval. These components involved the use of restraints to prevent feeding tube removal, the removal of those restraints contingent on taking oral medication (a form of negative reinforcement), and food deprivation and social isolation to increase the reinforcing effects of social praise and candy that were presented contingent on medication acceptance and swallowing. The contingent social praise and candy of course were a form of positive reinforcement, while contingent termination of social isolation and removal of the arm restraints were both conceptualized as negative reinforcement.

In the second case discussed in that article,[9] candy and praise were presented contingently to shape successive approximations of pill swallowing. These approximations included (1) touching her cheek and then lips with her index finger; (2) holding the pill between her index finger and thumb in a

pincer grasp; (3) touching the pill to her cheek, corner of her mouth, lips, teeth, and tongue; (4) placing the pill on her tongue along with sprinkled candy; and (5) swallowing the pill and candy together. In this case, 23 training sessions of 10–20 practice trials each were required for the child to learn to swallow the necessary pills. While the food deprivation and social isolation used in this study are not recommended and have not been repeated, this was the first published study that established some of the basic techniques that have been used to teach pill swallowing over the past 40 years. Specifically, these techniques include contingent positive reinforcement (praise, preferred items or activities) and naturally occurring negative reinforcement in which all pills (and stimuli related to pills) are removed from the child's sight after the presented pill is swallowed, and the child is allowed to leave the pill administration area to participate in play activities. These positive and negative reinforcement strategies are then employed to differentially reinforce successive approximations of the target pill-swallowing response.

Subsequent studies published during the 1980s were reviewed in detail elsewhere.[10] The reader is directed to this primary source to read an excellent article about pioneering behavioral intervention for pill swallowing in children. However, to summarize here, these studies employed (1) verbal instruction, demonstrations (modeling), and differential positive reinforcement for response shaping;[11-12] (2) relaxation training, planned ignoring, and time-out (for pill refusal and disruptive or avoidance behavior) combined with home rehearsal;[13] and (3) corrective verbal/demonstration feedback.[14]

Initially, differential positive reinforcement for swallowing successive approximations (gradually increasing sizes of candy "pills") was first introduced in the early 1980s.[12] Since then, the gradual introduction of increasingly larger candy "practice pills" or "mock pills" has become a standard part of most behavioral pill-swallowing training protocols.

In 1987, two additional cases were published in which a highly systematic behavior analysis–based protocol for teaching pill swallowing was demonstrated and its effectiveness documented using direct observation of pill size, pill acceptance or expulsion, type of prompting, and number of training sessions/trials required.[15] The two children were both 4-year-old girls of average intelligence with a chronic illness (hyperammonemia, severe asthma). One child required nine days with 10-minute sessions conducted three to six times per day. The other child required only one 75-minute outpatient session. The reader is encouraged to read the study[15] in its entirety because of the excellent procedural description provided and the careful specification of decision criteria for when to change practice pill

size based on the child's performance and the use of periodic probes with larger pills to determine if some of the fading steps might be skipped. For illustrative purposes, an excerpt from this article is provided here.

> Leeann was a four-year-old of average intelligence diagnosed to have hyperammonemia, an inborn error of metabolism that was identified at age 30 months. Because of the quantity and unpleasant taste of her prescribed daily liquid medicine, her pediatrician recommended that medication be administered in capsules. Her mother indicated that Leeann had attempted but never had successfully swallowed a capsule of any size.
>
> Prior to training, Leeann was asked to swallow a prescription-size #00 (23.7-mm) placebo capsule and a smaller "Tic-Tac" mint.
>
> Leeann did not swallow either one. . . .
>
> . . . Treatment sessions, each lasting approximately 10 minutes, were held three to six times daily and scheduled throughout the morning, afternoon, and evening. Treatment sessions consisted of five to ten practice trials. Each trial included handing Leeann a capsule, asking her to swallow it, and recording whether the capsule was swallowed or expelled. Although the typical number of trials per session was ten, fewer capsules were presented toward the end of training when Leeann was swallowing the prescription-size capsule. In this manner, daily medication administration requirements could be closely approximated.
>
> Treatment began by explaining to Leeann the advantages of learning to swallow capsules, particularly the fact that she would no longer need to take her unpleasant tasting liquid medicine. She was also informed that she could earn a star for a chart posted in her room if she swallowed 70% of the candy capsules given to her during each session. The actual number of successful swallows required to earn a star was stated to the child. The 70% criterion was chosen because it did not require that all presented capsules be swallowed successfully, thereby increasing the probability that Leeann would earn stars frequently. Leeann was allowed to exchange earned stars at the end of the day for preferred activities or small prizes if she earned a star during each session.
>
> The therapist, nursing staff, and Leeann's mother also provided praise contingent upon successful capsule-swallowing. Size-graded candies were then introduced. Leeann was instructed to place the candy on the back of her tongue, take a sip of water, tilt her head back, and swallow. This sequence was demonstrated by the therapist and by another child with congenital hyperammonemia who was able to swallow capsules easily.
>
> A gradually larger placebo capsule was presented each time Leeann met the 70% criterion. If the 70% criterion was not met, the size of the placebo capsule was decreased to the next smaller size during the next session. Except during the

first day of training with very small practice capsules, probes of the prescription size placebo capsule were conducted twice a day at the conclusion of a session. The therapist or Leeann's mother recorded whether the presented candy or capsule was swallowed or expelled. Both independently recorded capsule swallowing during 45% of the sessions and interobserver agreement was 100%. . . .

. . . During sessions 1 through 3, Leeann was unable to consistently reach the 70% criterion using "Tic-Tac" candy. Therefore, smaller size sequins and button dot candies were presented during Sessions 4, 5, and 6. These were swallowed without difficulty. During Day 6 (Sessions 7, 8, and 9), Leeann met criterion at the next two sizes of practice capsules ("Tic-Tac" mints and pharmacy size #3, 16.46-mm placebos), but still refused to swallow criterion-size placebos. On Day 7, she successfully swallowed size #2 (18.34-mm) placebo and phenylacetate capsules, as well as prescription-size placebo capsules during Sessions 11 and 13. Day 8 (Session 14) began with repeated presentations of prescription-size placebo capsules. Although several of these were swallowed successfully, the 70% criterion was not met.

Therefore, size #2 phenylacetate capsules were presented during Session 15. Thereafter, Leeann consistently swallowed at least 70% of the presented lactose or phenylacetate capsules. At the end of Day 9 (Session 20), Leeann was able to swallow all of her prescribed medication in pharmacy size #00 capsules. . . .

. . . Leeann's mother observed most of the training sessions. She received both verbal and written instructions regarding when and how to implement the contingency management procedures designed to promote Leeann's compliance. Prior to discharge, she demonstrated her ability to carry out the procedures independent of trainer feedback. Social validation questionnaires assessing the extent of satisfaction with the training procedures and its outcome were completed by Leeann's mother, two unit nurses, and the referring physician at discharge. Responses indicated a high degree of satisfaction with both the treatment package and its clinical effectiveness. . . .

. . . The therapist periodically contacted the mother via telephone in order to assess the performance of both the parent and child and to offer booster training if indicated. According to her mother's report, Leeann has continued to swallow all required capsules (15 size #00 capsules daily) for 6 months. The mother discontinued use of the star chart one week after discharge, and Leeann's compliance has been maintained, in part, through the use of intermittent verbal praise.

Reprinted with permission from Pelco, L.E., Kissel, R.C., Parrish, J.M., & Milternberger, R.G. (1987). Behavioral management of oral medication administration difficulties among children: A review of literature with illustrations. *Journal of Developmental and Behavioral Pediatrics*, *8*, 90–96.

The article discussed above illustrated the efficacy of a potentially brief and easily implemented training protocol employing verbal instruction, modeling, pill size fading, and contingent positive reinforcement with praise and tangible rewards to gradually shape swallowing practice pills of increasing size. When necessary to manage refusal behavior, gentle physical guidance of pill placement was added. It is interesting to note that in one of the cases increased medication acceptance resulted in medical improvement, whereas in the other case it did not. This supports an observation that is sometimes made in clinical practice that using behavior analysis procedures to ensure medication compliance can help to rule out noncompliance as the cause of poor response to medical treatment. In such cases behavior analysis can be used to highlight the need for an alternative medication or other approach to medical treatment.

Another important study in this line of research[3] used a single-subject experimental design to evaluate the effects of a capsule-swallowing training program designed for children with IDD and multiple handicapping conditions. Four children with IDD, ranging in age from 3.5 to 17.5 years, participated in the study. Three were functioning in the moderate range of IDD, and the fourth was in the profound range. All four had a chronic illness requiring them to take daily capsules. Three had inborn errors of metabolism requiring between 24 and 27 capsules daily. The fourth child had attention deficit hyperactivity disorder and asthma and required as many as three pills and three capsules daily. The children were treated as inpatients, and sessions were conducted in their hospital rooms. The training materials used included a glass of water, size-graded practice "pills" (sprinkle- and star-shaped cake decorations, Tic Tac mints, and #5 to #00 gelatin capsules), the child's actual medication, and reinforcers (stars, food, juice, preferred toys, makeup). Varying numbers of baseline probes were conducted throughout one day of baseline observation for each child to determine if the child could swallow the criterion-size capsule without training. During baseline assessment, the capsule and a glass of water were presented to the child and the child was instructed to swallow the capsule. The therapist made no comments in response to swallowing or not or to the occurrence of problem behavior such as chewing, gagging, spitting out the pill, head turning, blocking with hands, or negative vocalizations.

Behavioral training included verbal instruction, demonstration, reinforcement for swallowing candies/capsules of progressively larger sizes, and ignoring inappropriate behavior. In order to provide detailed descrip-

tion of the training procedures that are so thoroughly described by the authors and facilitate the reader's understanding of how to implement this protocol, an excerpt from the study[12] is presented below.

> After seating the child at the training table, the trainer stated it was time for the child to practice swallowing candies and/or capsules. She also informed the child of the opportunity for reinforcement, involving the presentation of preferred objects or events contingent on successful swallows. Each trial began with a specific onset (that is, a single presentation of the training stimulus, be it a candy or capsule, along with a request to swallow it) and ended with a specific offset (a specific consequence, such as praise). The trainer placed the selected stimulus as far back on the child's tongue as possible, and then handed the child a cup of water. She then asked the child to swallow the stimulus ("Sharon, please swallow your pill"). If the child swallowed the stimulus, the trainer provided praise and attention, and gave the child a reinforcer (for example, cookie) contingent on the child's demonstration that his/her mouth was clean. If the child did not swallow the presented stimulus or began to chew it, he/she was instructed to expel it into the trainer's hand. All inappropriate behavior was ignored and the child was redirected, if necessary, back to the task (oriented to be ready for the next presentation of the stimulus).
>
> Mastery criteria were set before training and dictated when the child had exhibited sufficient skill with a given sized stimulus to be eligible to begin practice with a stimulus next larger in size. In all cases, the child met the predetermined criterion for a graded-size capsule when s/he swallowed three consecutive capsules successfully, without the occurrence of any inappropriate behaviors. Each time the child demonstrated mastery, the trainer conducted a probe (i.e., a trial) with the criterion-size capsule to determine whether any additional training was required. Occasionally, these probes were omitted because of logistical constraints, the child's stated preference, or therapist omission. If the criterion-size capsule was swallowed during the probe, the trainer began the next session with the criterion-size capsule. If the criterion-size capsule was not swallowed successfully, the trainer increased the size of the training stimulus by one gradation and began a new session. For example, if a child swallowed three #5 capsules consecutively, the trainer would probe with the prescription-size #00 capsule. When the child was able to swallow the criterion-size capsule consistently (at least 80% successful trials across three consecutive sessions), new trainers (for example, parents and nurses) and new environments (locations other than the child's hospital room) were introduced to

promote generalization of the newly acquired capsule-swallowing skills and to increase the probability that the child would exhibit skills in other situations with other people.

Reprinted with permission from Babbitt, R.L., Parrish, J.M., Brierley P.E., & Kohr, M.A. (1991). Teaching developmentally disabled children with chronic illness to swallow prescribed capsules. *Journal of Developmental and Behavioral Pediatrics*, *12*, 229–235.

In the article quoted above, several procedural modifications were used with some of the children. These are important to note because they highlight the need for individualization of some aspect of the behavioral training procedures to meet the unique needs of each child. Specifically, the authors observed that empty gelatin capsules were so light that they stuck to the inside of the mouth, making it difficult for the child to swallow them. Consequently, capsules were filled with cornstarch to add weight and decrease the chances of their getting stuck to the tongue or inside the mouth. Another modification involved who placed the mock or actual pill in the child's mouth. Until the child self-initiated placing the pill in his or her own mouth, the therapist placed it. However, if the child attempted to place it in his or her own mouth, the therapist allowed the child to administer the mock or actual pill thereafter. If, after demonstrating routine acceptance of the prescription-size capsule, the child had not yet self-initiated placing it in his or her own mouth, the trainer placed the capsule into the child's hand and instructed him/her to place it independently on the back of the tongue. If a participant would accept the stimulus but refuse to drink water from a cup, a syringe was used to insert water through the lips to facilitate swallowing.

Another child had difficulty progressing through the hierarchy of the size-graded practice pills, and a tongue depressor was used to help him flatten his tongue so that the pill could be placed further back on the tongue. The use of the depressor was subsequently faded by one-quarter inch at a time as he achieved criterion at each gradation in size.

Finally, one child exhibited noncompliance with adult instructions, frequently clamping her mouth shut, having a tantrum, and refusing to swallow her pills. Therefore, if she had not accepted any capsules during a session, she was required to sit in her chair without attention for the duration of a session. Time-out was used for another child contingent on chewing or refusal. When these behaviors occurred, his high chair was turned away from the trainer for five seconds and all toys were removed for the time-out interval.

Sessions in this study ranged between 1 and 18 minutes each and included 10 separate presentations of practice pills until the mastery criterion of three consecutive successful pill swallows was met. The number of sessions required ranged from one to eight sessions daily, and the child was permitted at least 10 minutes of free play between training sessions. A successful trial was recorded if the pill was accepted and swallowed, which was confirmed by inspecting the mouth. The total amount of training time required for each child to demonstrate consistent acceptance of the prescription-size capsule also was recorded and summed across sessions. Single-subject experimental designs (nonconcurrent multiple baseline across subjects and changing criterion) were used to evaluate the effectiveness of behavioral training. In each case, the child learned to swallow pills/capsules, requiring between 26 and 57 sessions. Cumulative training time for each child ranged from 38 minutes to 10 hours. Follow-up assessments and parent satisfaction ratings supported that the results were maintained and clinically significant.

The above study extended the literature by documenting that children with moderate to profound intellectual disability can be safely taught to self-administer life-saving medication using a systematic training program based on applied behavior analysis. It is important to note that the authors did not intend for their training protocol to be used as a standard package for all children without modification. Indeed, they showed that a systematic strategy is important, but training procedures and target steps must be individualized to meet the specific needs and capabilities of each child. Importantly, they cautioned readers to consider the special risks and limitations of children with swallowing disorders or a history of food or liquid aspiration. In such cases the pill-swallowing protocol may not be appropriate, or at least would need to be conducted with caution and careful physician oversight.

A more recent study[1] applied a similar behavioral training protocol to teach four 5- to 6.5-year-old children with autistic disorder (AD) who also showed symptoms associated with attention deficit hyperactivity disorder (ADHD) to swallow pills. The children's verbal IQ, nonverbal IQ, and Preschool Language Scale-3 scores ranged from 50 to 107, indicating functioning in the intellectually disabled range for some children, while others were in the average to above average level of intellectual and language functioning.

In this study a package of teaching techniques were used, including verbal instruction, in vivo demonstration (modeling), gestural and physical

prompts, and visual aids (a small poster with an actual example of each of the increasingly larger practice pills). The chart showed the children the goal of the training, as well as the specific objective (pill size) for each training session, allowing the therapist to provide visual feedback on the progress the child made during the sessions. Another unique feature of the training provided in this study was the use of a separate therapy room for play breaks that were made contingent on successful pill swallowing. The therapist made this contingency visually concrete by showing the "break room" to the children and reminding them that after they were successful with pill swallowing they could leave the primary therapy room and enter the break room for a specified period of reinforcement. As in prior studies, the pill-swallowing training involved behavioral rehearsal sessions in which the children practiced swallowing mock pills (e.g., cake decorations, candy sprinkles, candy "dots") or capsules of gradually increasing sizes and, ultimately, placebo capsules that matched the size of the required actual medication but were filled with cornstarch. Training with each child was initially attempted with "candy pills" but was switched to capsules if the child consistently chewed the candy pills despite repeated prompting from the therapist not to chew them. In this study, because the children were quite young, hyperactive, and distractible, two therapists worked with the child in a distraction-free room to keep the child focused on the training stimuli. The caregiver watched from behind a one-way mirror.

The therapist interviewed the caregiver to assess the child's food and drink preferences and other potential reinforcers. Next, the child's ability to perform prerequisite behaviors when prompted was assessed directly. The prerequisites were (1) ability to follow one-step gross motor instructions (such as "Come here," "Sit down," and "Hand me the toy") and (2) ability to perform basic oral motor responses when prompted (i.e., "Open your mouth," "Say 'Ahh,'" "Stick out your tongue," and "Swallow"). If the child was not able to perform these prerequisites, he or she was taught by the therapist using demonstration, verbal and manual prompting, and differential reinforcement with contingent praise and tangible reinforcement (sticker, bite of preferred food, etc.). If the child had not mastered these skills, they became the focus of training before progressing to the presentation of practice pills.

After the prerequisites were mastered, the therapist assessed the size of practice pill the child could tolerate by presenting a hierarchy of sizes, one at a time, starting with the smallest size (e.g., candy sprinkles). Once this

was determined, pill-swallowing training sessions began using the largest-sized practice pill that the child could swallow without distress or gagging. The therapist placed the practice pill on the child's tongue with one hand and quickly offered the child's preferred drink with the other hand. The child was told to take a drink, and if the practice pill was swallowed, the therapist praised the child's success and delivered a tangible reinforcer (a sticker or a bite of a favorite food). If the practice pill was not swallowed, the therapist provided verbal feedback on the child's behavior in a calm and neutral tone of voice ("No chewing," or "No spitting") and then presented the same-size practice pill again. A break was provided every three to five trials or earlier, based on clinical assessment of factors such as the child's compliance, success, attending to task, activity level, and distress. The criterion used in this study for advancing to the next-size practice pill was the occurrence of two consecutive successful swallows at the preceding size. The practice pill hierarchy was designed such that each size was noticeably, but only slightly, larger than the one preceding it. At the conclusion of each clinic visit, the therapist had the child demonstrate his or her current skill level for the caregiver using the largest size of the practice pill the child had swallowed, thus modeling the pill administration routine for the caregiver and programming for generalization of the child's cooperative behavior in the presence of the caregiver.

The therapist coached the caregiver across sessions using verbal instructions, verbal prompting, and performance feedback, until the caregiver could obtain child compliance with pill swallowing on two consecutive successful trials. At the end of each session, the caregiver was encouraged to practice daily with the largest practice pill that the child had swallowed successfully for the caregiver during that clinic visit. Caregivers were instructed not to attempt to advance the practice pill size or to otherwise modify the pill routine at home, but to contact the therapist if the child experienced difficulties during the home practice.

The results of the study reviewed above[1] indicated that of this unique sample of children, two (50%) successfully learned to swallow the target-size capsules, one (25%) was able to swallow the target-size capsules with the behavior therapist but had difficulty with the caregiver, and one (25%) made slow progress and the training was discontinued by the caregiver, who chose instead to switch to a crushable pill medication. In relation to this caregiver's decision, the authors noted that many medicines have alternative formulations such as liquid, chewable, or crushable forms, but many other medicines do not have pediatric formulations, and chewing,

crushing, or opening the capsules may not be an option (e.g., bitter or unpleasant tasting, may cause irritation on contact, extended release).

Eight children with ADHD or AD participated in a subsequent but closely related study.[16] The pill-swallowing training protocol was conducted during practice sessions with practice "pills" of increasing size to implement the stimulus-fading and response-shaping procedures across the hierarchy of practice pills. The training was implemented in an outpatient clinic setting with the two groups of children. To summarize the procedures used during training, pill-swallowing skills were modeled by the therapist and practiced by the child. All pill-swallowing attempts were differentially reinforced with social and tangible reinforcement, and all nondangerous distress behaviors were placed on operant extinction (resulted in no reinforcement).

The results of this study showed that after behavioral training, seven of the eight children were able to swallow their prescribed actual medication in the clinic with a therapist, and six of the eight children were able to maintain this skill when caregivers administered the medication in other settings. Adjustments to the behavioral protocol were required to facilitate training with both groups of children. For example, children in both groups required breaks during training sessions, but those having only ADHD required fewer breaks (one 10-minute break per one-hour session). Children with AD cooperated better with brief sessions of 5–10 minutes with a two-minute break between sessions. Once again, the investigators used two separate treatment rooms for the children with AD: a "workroom," where pill-swallowing trials were conducted, and a "playroom," where the children went for between-session breaks. The more typically developing children with ADHD were able to transition successfully between demand and no-demand time periods within a single treatment room. The use of two separate rooms facilitated management of the child's disruptive (impulsive, hyperactive) behavior.

The children with autism also had difficulty with sequencing the oral motor skills involved in pill swallowing. To assist with this problem, a task analysis was developed to teach the responses (i.e., "Open mouth," "Stick out tongue, say 'Ahh' "). The children were prompted to perform these responses at the beginning of each visit and intermittently during the training sessions.

Another task analysis was developed to desensitize one of the children to pills being placed in his mouth because of his extensive head turning, eye closing, facial grimacing, and mouth clamping when the therapist

attempted to place the pill on his tongue. The task analysis included a desensitization hierarchy beginning with lightly touching the pill to his face and then lips. After he could tolerate this stimulation and open his mouth when prompted, he received reinforcement for tolerating the pill touching his tongue for one, two, and three seconds. Another modification involved cutting the pills into smaller sizes when children with AD had a tendency to chew them.

The investigators reported that the children with ADHD required minor adjustments to the protocol. These included teaching abdominal breathing exercises to manage child anxiety about choking, providing a mirror to encourage proper head position and pill placement for children who tended to tilt their heads too far backward when attempting to swallow the pills, and use of a timer and a "beat the clock" contingency for children who attempted to avoid or delay by holding or playing with medication in their mouths. For example, the child could earn a sticker if he could swallow within 30 seconds. The authors of this study also highlighted the fact that no research has systematically studied how parent behaviors impact the acquisition, maintenance, and generalization of pill-swallowing skills in their children.

Another important research question is whether or not systematic behavioral training of children to swallow pills ultimately improves medication adherence and child health status. Another recent study[17] assessed retrospectively the efficacy of pill-swallowing training for referred pediatric patients with HIV for evidence of improved adherence and health outcomes. First, they examined whether or not participation in pill-swallowing training was associated with improved medication adherence based on pharmacy pill counts. Then, they assessed the correspondence between medication adherence measured in this way and improvements in biologic indicators of adherence and health (CD4 T-cell count and viral load). The retrospective chart review was completed for 23 pediatric patients with HIV between the ages of 4 and 21 who were referred in order to receive pill-swallowing training by a pediatric psychologist. At baseline, medications were in liquid or powder form, or prescribed as pills to be crushed into a powder or capsules to be opened and the contents sprinkled in liquid or over food. The patients participated in individual training sessions in which pill swallowing was modeled by the therapist and then the patient practiced by swallowing pieces of "gummy worm" candy cut to match the size of placebo gel caps. After the patient was successful with the candy pieces, lactose-filled placebo gel caps were introduced. Both the candy pieces

and placebo gel caps were presented in gradually increasing sizes. The criterion for advancement to the next size was successfully swallowing two of the currently presented size without difficulty. As in the other studies discussed above, the number and the length of training sessions were determined by each individual's rate of progress and continued until the patient could swallow the prescribed pills or it was judged that he or she was not developmentally able to master pill swallowing. In most cases training sessions lasted between 15 and 30 minutes.

After training was completed and the patient could swallow the prescribed pills, adherence checks were conducted by a pharmacy technician using standardized methods. Adherence was measured by pill count and expressed as a percentage calculated using the number of pills returned by the patient in the prescription vial relative to the number of pills prescribed. During baseline when medications were prescribed in liquid form, adherence percentages were calculated based on the fluid volume of prescribed and returned medication.

At three- and six-month post-training assessments, medications were in pill form except for a few patients requiring that a study medication remain in liquid form for medical reasons. The modal number of sessions required for mastering pill swallowing in this study was reported to be 1. Younger children (ages 4–5) required a median of two sessions, and older children required three sessions. The authors also reported a significant improvement in medication adherence, CD4 T-cell count, and viral load. The authors concluded that there is good preliminary evidence that pill-swallowing training is a successful, time-limited, and likely cost-effective intervention to improve adherence with prescribed antiretroviral medication and ultimately to improve the medical status of children and youth with HIV. Based on these findings, the authors called for continued study via prospective, randomized, controlled clinical trials.

A recent development in the area of pill swallowing is the availability of a spray liquid lubricant that is commercially available under the name FLAVORx Pill Glide (http://flavorx.com/products/pill-glide/). It is sprayed on the pill or capsule and/or on the child's tongue or throat to prevent the pill from sticking to the moist membranes in the mouth and throat and to facilitate swallowing. To date, only one study[18] has been published in which the benefits of this pill-swallowing enhancement aid were assessed. In that study a convenience sample of adolescents ranging in age from 9 to 17 were identified through self-report of having experienced difficulty in swallowing tablets or capsules. The participants were provided Pill Glide,

and Tic Tacs were used to simulate medication. Seven of the 11 participants were successful in swallowing the Tic Tac with the use of Pill Glide. This pilot study suggested that Pill Glide spray can help to improve the ease with which adolescents can swallow pills.

In another recent development in the pill-swallowing literature, a novel approach was developed based on published research showing that changing head position alters swallowing dynamics.[19] The investigators sought to learn if children who had never been able to swallow a whole pill could learn to do so using an intervention based on head posture. The intervention protocol was developed in studies of 240 adults and children, pilot tested in a study of 108 university students with mild pill-swallowing discomfort, and finally applied in a study of 41 children who had never successfully swallowed a pill in spite of considerable effort to do so. The participants were hospital clinic patients (34), siblings or friends of these patients (4), and children of hospital staff members (3). The intervention first taught five head positions (center, up, down, left, and right) and then assigned two weeks of daily practice. During the first session, the children were shown a diagram of the size of the esophagus, which is larger than any typical pills. They were educated about the flexibility of the soft tissue in the esophagus, and they were told about the funny "ngunk" noise their throat makes when they swallow water with their heads turned off-center (this may be the sound of increased cricopharyngeal opening and/or decreasing upper esophageal sphincter pressure). Candies of varying sizes and a practice pill of 100 mg lactose were used for training. The five head positions were introduced using sips of water. Feedback on correct posture was given when needed, and then the children were encouraged to try the positions using a small candy. They were allowed to select the candy they wanted to use for their practice each night. One child chose to progress from smaller to larger candies, but most children used only a few different sizes and then quickly progressed to the largest when they discovered a preferred position and succeeded in swallowing the candy/practice pills. Follow-up phone calls were conducted after 30 days to determine if the children had been able to successfully take their prescribed medications. Eight of the clinic-referred children withdrew without practicing, four were too ill to practice, and four were nonadherent with the assigned home practice. All of the clinic-referred and healthy control children who were able and willing to practice daily for 14 days were reported to be successful with their prescribed medication. For the interested reader, a training video can be viewed at www.ucalgary.ca/research4kids/pillswallowing.

While the above study is intriguing and the results are encouraging, this intervention has yet to be replicated by any other group of investigators. It also has not been compared to a control condition in which children practice with candies/mock pills for two weeks but are not taught the five head positions. Further research on the physiology of the varying head positions is needed to determine if any particular position mechanically facilitates pill swallowing.

Thus far the literature review in this chapter has focused primarily on oral medication in pill or capsule form. However, it should be mentioned that applied behavior analysis can, and has, been used to increase child compliance with liquid medications as well.[20]

Establishing child acceptance and swallowing of liquid oral medication is quite similar to the task of getting young children with food refusal to eat and drink. There is extensive applied behavioral research literature on this topic. This research will not be discussed here, but the reader is directed to any number of excellent articles on the topic for more information.[21–23] Other behavior analysis studies have demonstrated procedures for teaching a basic swallow response in children who do not eat or drink.[24–26] The same principles of differential positive and negative reinforcement, response shaping, stimulus fading, and escape extinction which apply to treating food and liquid refusal also apply to training liquid oral medication acceptance and swallowing.

In relation to liquid medication adherence, one preliminary study[27] in recent years assessed benefits of a commercially available flavoring for liquid medication (FLAVORx). In that study, 30 Thai children (mean age of 5.2) were required to take opened capsules, crushed tablets, and liquid generic antiretroviral medication for management of HIV infection. Based on a standard international questionnaire and interview before and after one month of using FLAVORx, 80% were reported by parents to be able to take their medication with greater ease using FLAVORx and wished to continue using it. Incidentally, in that sample, strawberry was the most popular flavor.

10.6. CLINICAL CASE EXAMPLES

In recent work on pediatric pill swallowing by the author and colleagues,[1] the individual variables representing barriers to pill swallowing were examined in 11 clinical cases ranging in age from 5 to 15. These children and adolescents were being treated for a variety of medical and behavioral

disorders and included individuals with and without developmental disabilities. This study demonstrated the use of evidence-based practices, as discussed in this chapter, as well as additional individualized procedures to address case-specific barriers to mastery of pill swallowing. The participants required a mean of five training sessions (range: 1–11). Predictably, 9 of the 11 participants simply lacked the oral motor skills necessary to swallow a pill of the size prescribed. However, in addition to the need to learn the oral motor skills, seven individuals exhibited either generalized or medication-specific anxiety, seven displayed escape/avoidance behavior, four were behaviorally noncompliant with adult instructions, six displayed aversion to the unique shape or texture of their prescribed pills, and in five cases progress was impeded by parental variables that interfered with their follow-through on implementing recommended behavioral procedures. To solve these barriers, a creative problem-solving approach was implemented in which a variety of procedural modifications were added, including (1) creation and use of a visually displayed task analysis of the steps involved in successful pill swallowing; (2) special verbal prompts such as "no chewing" or "no swishing"; (3) special physical/manual prompts such as chin or head positioning; (4) unique swallowing aids such as thickened liquids, particular food chasers, Pill Glide lubricating spray, or drinking the liquid chaser with a straw; (5) variations in the schedule of reinforcement such as high-density activity or edible reinforcement immediately after each discrete trial or delayed reinforcement provided at the end of the training session; (6) stimulus-fading variations such as skipping certain sizes or shapes or cutting stimuli into intermediate sizes; and (7) general parent training and/or general child compliance training. With various combinations of these individualized modifications, all of the youth were able to master swallowing their prescribed medication.

It was interesting to note that there was a lack of correspondence between required pill size and the number of training sessions required, which further highlighted that multiple variables contributed to the rate of a participant's progress in training. As an illustrative example, the authors presented session-by-session procedures and modifications employed to teach a 10-year-old boy with pervasive developmental disorder, obsessive-compulsive disorder, and oppositional defiant disorder. Over the course of nine training sessions, all of the different types of procedural modifications described above were employed along with discrimination training in which the child learned that during pill-swallowing trials ("work time") he was not to chew the pill stimuli, but during reinforcement intervals

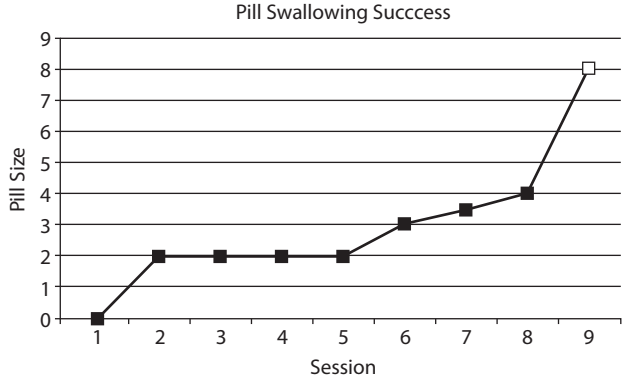

Figure 10.3 Pill size (*vertical axis*) successfully swallowed by a 10-year-old male with pervasive developmental disorder, obsessive-compulsive disorder, and oppositional defiant disorder across behavior skill training sessions (*horizontal axis*). The filled squares indicate sessions when practice pills were presented, and the open square indicates the session when the actual prescribed pill was presented and successfully swallowed. Reprinted with permission from Marocco, L., Bierenbaum, M., Spencer, K., et al. (2011). Pediatric pill swallowing: One size doesn't fit all. American Psychological Association, Division 54, National Conference on Child Health Psychology, San Antonio, TX.

("chew time") he was allowed to chew his "chewy candy." Outcome data from that case are shown in figure 10.3.

The results of this series of clinical cases[1] illustrate that successful pill-swallowing training often requires ongoing assessment, intervention conceptualization, and creative problem solving to address the idiosyncratic nature of barriers to pill swallowing. Although this process may seem time-consuming and expensive, it must be considered in relation to the very significant health risks associated with medication nonadherence in youth with chronic medical, behavioral, and/or developmental disorders along with the lifelong benefits of mastering a pivotal medical self-care skill.

KEY CONCEPTS

- Many children have difficulty accepting medication of some type, especially during early childhood.
- Many medications routinely prescribed for children are flavored and sweetened to appeal to children.
- When medication is not already flavored for children, many pharmacies are able to add child-preferred flavoring.

- One problem with flavoring medication is that the unpleasant taste of some medications cannot be effectively disguised and the child may develop taste avoidance for both the medication and the flavoring.
- Caregivers are cautioned not to mix medication in a child's favorite food because under some circumstances the child may stop eating it and similarly tasting foods, or may start avoiding food altogether.
- Learning to swallow pills or capsules is often an effective solution to medication noncompliance.
- There have been relatively few published studies about behavioral approaches to teaching children and youth to swallow pills and capsules.
- Verbal instructions, demonstration (modeling), pill size fading, and differential positive reinforcement to gradually shape ability to swallow practice pills of increasing size have been the fundamental techniques used to teach children to swallow pills/capsules.
- The same behavior principles and similar procedures are used when liquid medication adherence is the objective.
- The extensive research literature on getting children with feeding disorders to eat and drink has relevance to and suggests procedures that can help to improve liquid medication compliance.
- Children with moderate to profound intellectual disability and neurobehavioral disorders such as hyperactivity and autism can be safely taught to swallow pills/capsules using a systematic training program based on applied behavior analysis.
- Research on pill/capsule swallowing continues and includes study of the benefits of liquid spray lubricant, modifications in head position, and more highly individualize teaching methods.

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Adherence with Oral Medication and Other Medical Self-Care

IN THIS CHAPTER

- Individuals with chronic medical conditions must adhere with a variety of medical self-care tasks on a daily basis in order to manage disease and maintain optimal health.
- This chapter focuses on adherence with oral medication and diabetes self-care in children and adolescents because the research literature is better developed in these areas.
- The behavioral and environmental variables that influence adherence with these activities are similar across many chronic medical conditions and regimens required to treat them.
- Motivation, response effort, skill mastery, social support, planning, organization, and memory abilities are variables that influence adherence across conditions and regimens and are considered here.
- Methods of assessment and measurement of adherence are reviewed.
- Barriers to adherence and intervention strategies to improve adherence are discussed.
- Supporting literature and a case example are presented.

11.1. PATIENT POPULATION AND TARGET PROBLEM(S)

Ingesting oral medication, conducting blood glucose tests, administering injections, performing breathing (e.g., nebulizer) treatments, wearing a breathing mask while sleeping, self-catheterization, and suctioning a

tracheostomy are some of the many health care procedures with which individuals with chronic medical conditions must adhere on a daily basis in order to manage disease and maintain optimal health. This is the case whether the patient is an infant, toddler, teenager, or adult and regardless of level of intellectual and developmental functioning. Of course, the extent to which responsibility for maintaining adherence lies with the patient or a caregiver varies with the age and the intellectual and developmental functioning of the child. In many cases the child is completely dependent on the parent or caregiver to administer care and adhere with a prescribed regimen. However, as children become older and increasing their independence is developmentally appropriate, the responsibility for adherence must begin to transition from the caregiver to the patient. Negotiating this transition can be a complicated and challenging process for children and their caregivers. An extensive amount of research has and continues to be conducted on how best to ensure medical regimen adherence across developmental phases. A portion of that research and assessment and intervention procedures resulting from that research are presented below.

This chapter focuses primarily on adherence with oral medication and diabetes self-care in children and adolescents because the research literature is well developed in these areas. Nonetheless, the behavioral and environmental variables that influence adherence with these activities are similar across most chronic medical conditions and regimens required to treat them.

11.2. ASSESSMENT AND MEASUREMENT

Assessing and measuring adherence is not an easy undertaking. The most common approaches to measuring adherence have relied on interviews and questionnaires. The investigators in this area have developed a set of standards for increasing the chances of obtaining valid responses to these assessments. For example, interviews are conducted using a structured format, nonjudgmental wording of questions, and a short time period such as over the preceding week; interviewing the child and caregiver separately; normalizing occasional nonadherence; and prompting for recall of barriers to adherence.[1] Adopting these standards, some researchers[2] developed the Medical Adherence Measure (MAM), which is a structured interview assessment of patients' knowledge about their medication adherence behaviors, organizational systems, and barriers to adherence and disease management over the past week. Patients are asked if they have encountered

each of 12 commonly occurring barriers to adherence. They are also asked to indicate the number of doses of each of their medications they have missed over the past seven days. The MAM has been studied and shown to have acceptable reliability and validity.[2–3]

Another established method for measuring adherence involves conducting a medication quantity count either in clinic or by phone to determine the number of pills or amount of liquid remaining relative to the prescribed amount, dosage, and schedule.[4–5]

A number of other methods for measuring adherence with medication and other disease management regimens have been developed by researchers studying adherence to diabetes management in children and adolescents. These measures are nearly always indirect, proxy measures used to estimate adherence because they involve parental and child behaviors that are not easily directly observed by researchers. While self- and parent-report interviews and questionnaires have been studied and validated, their correlation with biochemical measures of diabetic control is not consistently high. Furthermore, adherence tends to be overreported by children and caregivers, and their reports do not always correlate well with each other.[6]

The Diabetes Self-Management Profile, one of the better-structured interview approaches, was developed to measure diabetes adherence.[7] For this assessment the respondent is asked to estimate the frequency of occurrence of 25 self-management behaviors during the preceding three months. This structured interview results in a total adherence score, as well as subscores for five components of diabetes management: exercise, diet, glucose testing, management of hypoglycemia, and insulin administration. The developers have published data to support acceptable test-retest reliability and showing that total scores correlate moderately with hemoglobin A1c levels (a biological measure of longer-term diabetes control). It is important to note that the validity of the data obtained from the Diabetes Self-Management Profile can be increased by following specified interview standards. The recommended standards are listed in table 11.1.

There also are technological measures of some aspects of adherence. For example, with respect to diabetes management, modern blood glucose meters can automatically store in memory the date, time, and results of blood glucose testing.[6] For children being treated with stimulant medication such as methylphenidate for attention deficit hyperactivity disorder (ADHD), medication adherence can be validated using methylphenidate saliva assays, a biological measure similar to testing hemoglobin A1c blood

TABLE 11.1 Recommendations for Use When Assessing Adherence with Medication or Other Disease Management Regimens

1. Use a trained interviewer who is not a member of the clinical treatment team
2. Interview parents and youth separately
3. Conduct the interview outside of the medical clinic
4. Introduce each section of the interview with comments that normalize occasional nonadherence
5. Clearly specify the time frame over which adherence is being assessed
6. Refrain from judgmental or emotional reactions to reports of nonadherence

Source: Wysocki, T. (2006). Behavioral assessment and intervention in pediatric diabetes. *Behavior Modification*, *30*, 72–92. Reprinted with permission from Sage.

levels in patients with diabetes. Using methylphenidate saliva assays, one recent large-scale study found that 25% of the samples indicated medication nonadherence, almost 50% of the parents were inaccurate in reporting their child's medication adherence, and only 53% of the participants were adherent at every time point assessed in the study.[7]

Another technological method for measuring adherence with medication involves the use of electronic medication container caps that record the date and time whenever the container is opened. This approach can be used as part of a multi-method, multi-informant approach but is limited by the fact that it does not directly verify that the medication has been ingested, only that the container was opened at the prescribed time.

The Medical Event Monitoring System (MEMS) SmartCap or TrackCap (AARDEX Ltd., Union City, CA) has been used in studies of antiretroviral medication adherence in HIV-infected children,[8] vitamin and mineral supplement adherence in pregnant low-income women,[9] immunosuppressive medication adherence in children and adolescents after kidney transplant,[10] and stimulant medication adherence in children with ADHD,[11] to mention only a few areas of application. MEMS caps contain an embedded computer chip, which digitally records when pill containers are opened. This methodology assumes that when the cap records that the container was opened, the prescribed pill(s) were removed and ingested. Using the data provided by the MEMS, researchers and clinicians can analyze daily adherence to prescribed dosages, administration times, and any missed or unscheduled doses. MEMS is not without its problems, the most notable being that patients have been known to open the container but not remove the medication dose, or if they remove the medication, they may not actually ingest it (throw it away, hide it, etc.). For this reason, MEMS is

typically employed along with other measures such as medication diaries, pill counts at clinic visits, telephone interviews, and pharmacy records of prescription refills.

Research has been conducted to compare adherence rates across various combinations of these measures of adherence. For example, one study[8] obtained adherence rates in HIV-infected children ranging from 12.7% to 97.9% with a median of 81.4% using MEMS. Accuracy of adherence measures is important in this population because the antiretroviral medication prescribed requires a high rate of adherence to sufficiently suppress viral load and maintain health. For example, a MEMS adherence rate greater than 80% was associated with a viral load below the threshold of detection at six-month follow-up assessment.[8] Pharmacy refill data alone were also negatively associated with viral load, but not as strongly as MEMS data. The combined use of MEMS and pharmacy refills was most strongly associated with suppression of viral load. Caregiver report of adherence was the least well associated with decreased viral load.[8]

In another study, adherence rates of expecting mothers with prenatal vitamins and supplements were assessed using self-report, pill counts, and MEMS. In that study mean adherence was 68% measured by MEMS, 77% measured by self-report, and 84% measured by pill count. These results indicate that pill count and self-report may overestimate adherence, and the authors applied linear regression to adjust for measurement error.[9] This adjustment was based on the assumption that MEMS is the "gold standard" of measurement for medication adherence, which may be a faulty assumption given that activation of the MEMS cap does not assure that the medication was ingested.

One study[10] found that the MEMS technology was not readily accepted by pediatric kidney transplant patients. In that study participants completed a debriefing form about their experiences with MEMS. One significant problem was that many of the younger patients were prescribed liquid medication, with which the MEMS technology is less feasible. Further, many patients rejected the MEMS entirely, and others dropped out because they did not want to use the MEMS. Of those who completed the study, 41% found transferring their medication into the MEMS container to be difficult. Some of the patients (27.2%) found it burdensome to carry the container, and 22% felt that it changed their daily routine. Finally, 10.2% reported that using the MEMS made them worry more about missing their medication, which they apparently perceived as negative, although it is possible that some degree of worry may actually facilitate adherence.

Another study examined the validity, inter-rater reliability, and stability over three months of a semistructured telephone interview, the Stimulant Adherence Measure, in comparison to MEMS in children (mean age 11.85 ± 2.1) with ADHD receiving psychostimulant medication.[11] The results of this study indicted correlations ranging from 0.66 to 0.87 between parents' seven-day reports and MEMS. For parents' reports of adherence over the preceding 28 days, correlation with MEMS ranged from 0.79 to 0.90. These data indicate strong agreement and support the validity of the telephone interview approach to monitoring medication adherence. Agreement between MEMS and child report, although not as strong (range: 0.54–0.77), was reasonably good. Inter-rater reliability results were also excellent (r = 0.95). Thus, there was good evidence for the usefulness of the semistructured telephone interview method of tracking medication adherence at least in the ADHD population studied.

Altogether there are many options to assessing and monitoring medication adherence, but there are limitations to the usefulness of each. Biological measures such as blood, urine, or saliva assays can determine the concentration of medication in a sample at a given time. A specialized assay such as hemoglobin A1c in blood samples can track longer-term glycemic control in patients with diabetes. However, these tests tend to be expensive and time-consuming and are invasive to the patients. Indirect measures such as pill counts and electronic monitoring devices such as MEMS can provide a useful estimate of the number of doses taken and missed but provide no information about antecedents to nonadherence. These methods also become more cumbersome when tracking adherence to multiple medications. Finally, research suggests that in general parent and child reports tend to overestimate adherence, yet they can include information about the reasons medication doses are missed.[11]

In terms of practical use for clinical monitoring, adherence measures by MEMS and self-report questionnaires tend to be, at least, moderately correlated.[12] A recent study conducted a meta-analysis including 11 studies and a combined sample of 1,684 patients from the literature between 1980 and 2009. In this analysis the mean of adherence measured by MEMS was 74.9% (range 53.4%–92.9%), compared to a mean of 84% (range 68.3%–95.0%) using self-report questionnaires. The correlation between these two approaches to measurement ranged from 0.24 to 0.87, and the pooled correlation for the 11 studies combined was 0.45.[12]

In the end, the choice of medication adherence measures must be tailored to the goals of the clinician, the resources available, and the intended

TABLE 11.2 Strategies for Multi-method Assessment of Medical Regimen Adherence

Pill counts
Self-report records
Periodic telephone interviews
Pharmacy refill records
Intermittent biological measures (blood, urine, or saliva assays)
Medical Event Monitoring System (MEMS) SmartCap or TrackCap (AARDEX Ltd., Union City, CA)

use of the data. Perhaps the simplest and most practical approach is to combine assessment methods, which tend to complement each other and increase the accuracy of the resulting data.[12] One such approach would be the combination of semistructured telephone interviews, pill counts, and pharmacy refill records (see table 11.2).

Considerations for Family Caregivers and Health Care Providers: Barriers to Adherence

In general, most medication regimens require adherence of 80% or better to be effective. While adherence rates vary somewhat by condition and regimen, it is not uncommon for studies to determine actual rates of adherence to be 50% or lower.[1,6-7,13-15] At younger ages, adherence is largely a function of parent behavior and their ability to understand the importance of the regimen and to manage their child's daily schedule and behavior. Adherence tends to be an increasing problem during the adolescent years, when parents begin to transfer responsibility for adherence to the adolescent and to decrease their own oversight of medication ingestion or performance of medical self-care.[13]

Some research also indicates that adherence is lowest when symptoms are in remission or well managed, the child is feeling well, and the medication is taken to maintain health rather than to treat active, distressing symptoms.[16-17] Other variables that have been associated with poorer adherence include health problems such as depression and children having poorer coping skills,[1,18-20] developmental transition (e.g., from childhood to adolescence), and psychosocial challenges such as a death in the family or a change in caregiver.[14] Another study[21] obtained self-report informa-

tion from the caregivers of HIV-infected children on the variables that decreased adherence with antiretroviral medication. The variables associated with poor adherence were difficulty swallowing pills or distasteful liquid medication, difficulty with giving medication with prescribed timing relative to meals, forgetting, change in daily routine, busy caregiver schedule, and time spent away from home. Also identified were problems with the child hiding the medication, too frequent or inconvenient dosing schedule, concerns about disclosing the child's illness to others in the community, and difficulty identifying backup caregivers who can ensure child adherence when the primary caregiver needs to be away from the home.[22]

In a 2004 study, the author of this book and colleagues reviewed 32 inpatient cases with HIV who had been admitted over a five-year period to a pediatric medical rehabilitation unit and were referred for behavioral psychology services to assess and treat their barriers to medication adherence.[23] These patients had been admitted because of their severe nonadherence, which put them at high risk for life-threatening health complications. The patients ranged in age from 20 months to 17 years, and 53% of the sample had known cognitive delay. The primary caregivers were quite varied and included both biological parents (3%), biological mother (25%), biological father (13%), aunt (31%), grandmother (16%), brother (3%), and foster care (9%). The patients' length of hospital admission ranged from 7 to 125 days (average of 41 days). Their inpatient admissions allowed for direct observation of adherence-related behavior and detailed assessment of barriers to adherence. The treating clinicians employed functional assessment and task analysis approaches to identify and operationalize specific barriers to be modified, if possible, using behavioral intervention. Barriers were identified and classified into three categories: *child/adolescent variables*, *caregiver/environmental variables*, and *medication regimen variables*. Resulting group data were summarized in terms of the percentage of cases for which each specific barrier was identified and the corresponding intervention that was employed. On average, seven barriers were identified for each participant (range 1–14). For younger children (ages 20 months to 10 years) the most frequent child-related barriers were their escape/avoidance behaviors (spitting, head turning, and other refusal behaviors) and difficulties with conditioned nausea and vomiting. For the same age group there were five frequently identified caregiver and environmental barriers: lack of organization of the medication routine, lack of appropriate supervision of medication taking, caregiver allowing the child to escape taking the medication, lack of provision of positive reinforcement for taking

medication, and lack of general behavior management skills. Finally, for this age group the most common medication regimen–related barriers were the specific form of the medication (large size or number of pills, unpleasant taste of liquid medication) and medication side effects such as causing nausea and vomiting.

The results for adolescents (ages 12–17) were examined separately. The most frequent adolescent barriers included behavioral escape/avoidance, general behavioral noncompliance, illness- or treatment-specific anxiety, denial of illness, and lack of knowledge about HIV and the importance of treatment. Similar to the younger group, the most frequent caregiver/environmental barriers were lack of organization of the medical routine and lack of appropriate supervision by a responsible adult. Finally, with the adolescents, the most common medication regimen barriers were the form of the medication (number and/or size of pills, unpleasant taste), negative side effects, and viral resistance to the prescribed medication (medication was ineffective despite adherence).

Based on the study discussed above,[23] the authors developed a checklist, which is presented in table 11.3. This checklist can be used during a clinical interview to prompt the interviewer to consider and inquire about the many different barriers that may be impacting a child's or adolescent's medical adherence.

The analyses described above were followed by analyses of the clinical interventions that were provided to address the identified barriers for each child. Data on interventions provided were also analyzed by frequency of occurrence across the younger, older, and combined age groups.[23] Intervention strategies resulting from the intervention analysis are presented in the next section of this chapter.

Other investigators have identified additional caregiver variables impeding adherence which were not included in the above analyses, such as caregiver drug and/or alcohol abuse or the caregiver also having a chronic medical or mental health condition. These are complex barriers that negatively impact a child's medication adherence and are very challenging for behavior therapists or other clinicians to address.[24] Such problems often require a concerted multidisciplinary effort and at times may even require involvement of Child Protective Services.

In a recent study examining the barriers perceived by adolescents with inflammatory bowel disease and their parents to interfere with medication adherence, the most frequently identified barriers were forgetting, interference with other daily activities, aversive side effects, unpalatable taste, poor

TABLE 11.3 Barriers to Adherence Checklist to Guide a Clinical Interview

Child/Adolescent Variable	Check If Identified	Notes
Behavioral Escape/Avoidance (e.g., spit, refuse)		
General Behavioral Noncompliance		
Conditioned Nausea/Vomiting		
Anxiety (illness or treatment specific)		
Skill Deficits (e.g., pill swallowing)		
Depression		
Avoid Acknowledgement of Illness		
Not Wanting Others to Know		
Lack of Understanding/Knowledge		
Other		
Caregiver/Environmental Variable		
Lack of Organization of Medication Routine		
Lack of Appropriate Supervision		
Allowing Escape		
Lack of Provision of Reinforcement		
Lack of General Behavior Management Skills		
Lack of Knowledge/Understanding		
Lack of Support/Help		
Lack of Resources (time, money, transportation)		
Own Illness/Medication Adherence Issues		
Other		
Not Wanting Others to Know		
Depression		
Medication Regimen Variable		
Form of Medication Administration (e.g., number or size of pills, taste)		
Side Effects (e.g., vomit)		
Resistant—Medication Not Effective		
Unmanageable Routine		

Source: Adapted with permission from Amari, A., Beck, M., Piszczor, R., Wertalik, G., & Slifer, K.J. (2004). Assessment of barriers to medication compliance in pediatric HIV patients: A pediatric psychology consultation clinic review of cases. Society for Pediatric Psychology, APA Division 54, National Conference on Child Health Psychology, Charleston, SC.

organizational abilities, failure to refill prescriptions, not being at home at scheduled medication times, difficulty swallowing pills, oppositional adolescent behavior, family or parent-child conflict about taking medication, and the complexity of the medication regimen.[25]

Similarly, in a study of the factors influencing parents' adherence with giving medication to their children with asthma, the variables associated with better adherence were understanding the benefit or effectiveness of the medicine, mastering the skill of administering the medication, family support, having a family routine, less anxiety about medication side effects, and better explanation about the regimen from the doctor.[26] Taken altogether, these studies document the great complexity of reasons why a child or adolescent may have difficulty maintaining adherence with medication or other medical self-care regimens.

Pediatric psychology research has thus shown that suboptimal adherence is influenced by (1) characteristics of the child, such as difficulty swallowing pills and avoidance of medication that tastes bad or causes noticeable side effects; (2) characteristics of the caregiver and family, such as drug abuse, forgetfulness, family conflict, poor parenting skills, low expectations about medication efficacy, and dissatisfaction with the medical team; and (3) characteristics of the medication or regimen itself, such as unpleasant taste or regimen complexity.[5,23,27–31] Finally, there is evidence from recent studies that a greater number of such barriers increase the probability of poorer adherence.[16,32–33] Most of the literature over the past decade has focused on identifying the myriad risk factors for child, adolescent, and caregiver nonadherence. What has become undeniable is the great complexity of solving the problems contributing to nonadherence.

11.3. INTERVENTION PROCEDURES

Some general conclusions can be drawn from the research discussed in this chapter. Measuring and verifying medication adherence is a challenging undertaking with no foolproof "gold standard." Therefore, whenever possible, a multi-method assessment using a combination of approaches is recommended.

There are numerous individual, family, peer, and health care system barriers that can interfere with adherence, and they need to be systematically evaluated on an individual patient basis. Findings from barrier assessments can help identify specific variables to be targeted for intervention using behavioral interventions. There is ample evidence that behavioral

interventions are more effective than educational interventions alone. Behavioral interventions using positive reinforcement, contingency management, and behavioral contracts to strengthen specific adherence-enhancing behaviors have established empirical support. In addition, group or family interventions that also target adherence-promoting behaviors such as coping skills, problem solving, and conflict resolution in both the patient and his or her social support network appear to have beneficial effects on establishing and maintaining medication adherence in youth with chronic health conditions.

Although numerous variables in the individual, regimen, family, and community influence adherence with medication in children and youth, many of these variables either cannot be changed or are extremely complex and challenging to change. It has been recognized to a greater degree over recent years that managing the psychosocial and behavioral aspects of pediatric chronic illness requires additional resources for the child and family above and beyond what is typically provided by medical professionals. In most major medical centers, services provided by counselors, social workers, psychologists, and behavior therapists are understood to be nearly as important to health and disease management as the medication that is prescribed.[15] After thoroughly assessing the barriers in the child's life which interfere with adherence, behavioral intervention must be implemented to target changes in the child's environment and social system which help overcome those barriers. Interventions must also provide organizational structure, carefully negotiated prompts and feedback for adherence, and social and tangible reinforcement for adherence behaviors. Extrinsic reinforcement contingencies are often needed to motivate child and family behaviors that are essential to adherence with a complex medical self-care regimen because the naturally occurring incentives for adherence are too few or remote and the negative consequences of nonadherence are not always immediately experienced. When it comes to caring for any particular patient, a thorough behavioral assessment and analysis of modifiable individual, regimen, family, and environmental variables are needed. This type of analysis and development of individualized intervention procedures is the forte of behavior analysts and behaviorally trained therapists.

Recommended behavioral interventions include self- and caregiver adherence monitoring, goal setting, reinforcing medication ingestion with tangible rewards, arranging contingency contracting with specific reinforcement for meeting adherence goals, problem solving, and linking the medication schedule to established routines such as meals, school, and bedtime.

Some further examples will shed light on the functional analysis approach that can be used to address identified barriers. In many cases children or adolescents have never received positive reinforcement for taking their medication, and providing reinforcing contingencies is recommended for these patients. Similarly, many patients do not receive adequate adult supervision of their medication regimen. Naturally, one intervention for these cases is to recommend increased adult supervision and to provide a record-keeping format that would allow the caregivers to document that they have supervised medication administrations.

For younger children, operant escape behaviors are common barriers and may be addressed by training caregivers to implement escape extinction and negative reinforcement contingencies (e.g., escape behavior is prevented or blocked, and medication taking is reinforced with subsequent contingent escape from the medication-taking situation after the medication is accepted and swallowed).

Another common barrier is caregivers' lack of general child behavior management skills, and in cases where this is a problem, the caregivers should be provided general child behavior management skills training. When families lack the daily structure of a medication routine, a behavior therapist can help them develop and implement a routine using written and/or picture schedules and data sheets to record medication administration.

If the unpleasant taste of the medication is a barrier, intervention involves masking the taste of the medication using physician-approved flavoring or teaching the child to swallow capsules and then recommending a switch to that medication format. As can be gathered from this discussion, the behavior analysis approach to assessing barriers to adherence and designing practical interventions to overcome them is highly flexible and ideally suited to individualized behavioral treatment of medication nonadherence.

11.4. SPECIAL CONSIDERATIONS AND CHALLENGES

Oftentimes there are complex barriers that negatively impact a child's medication adherence and are very challenging for behavior therapists or other clinicians to address. These may include caregiver substance abuse or addiction, as well as the caregiver having significant psychosocial, medical, and/or mental health problems. Family financial challenges may result in parents who work two or even three different jobs, and this can make being home to administer medication or supervise its ingestion next to

impossible. Such problems often require a concerted multidisciplinary effort to problem-solve and coordinate intervention. Caregivers may need to call on extended relatives, friends, teachers, or home-health nurses to provide the necessary organizational structure, supervision, and reinforcement contingencies to ensure adherence. In some cases the involvement of Child Protective Services may be necessary. These situations can be emotionally charged and highly stressful for the child, family, and professionals involved. Under these circumstances, it is important for the multidisciplinary professionals (physician, nurse, behavioral psychologist/therapist, social worker, and child protection agency staff) to communicate effectively and to coordinate intervention efforts and interactions with the child and family.

Family caregivers may need assistance with obtaining services for their own medical or mental health problems. Furthermore, when the child or caregiver has cognitive difficulties, additional strategies for communication, organization, memory aids, and professional supervision may be necessary.

When parents are separated or divorced and the child lives in two or more households over the course of a week, the transfer of medication, monitoring sheets, and other organizational aids often breaks down. In these cases duplicate medication supplies and adherence-related materials may need to be provided in all of the households.

As discussed in the preceding chapter on pill swallowing, a great many problems can be solved with behavioral intervention and patience. However, intervention efforts may take considerable time and look unpleasant before adherence is significantly improved (see chap. 10, sections 10.3 and 10.5).

Finally, for individuals with chronic medical conditions, adherence is a lifelong challenge. Considerable variability in adherence may occur over time depending on the prevailing life circumstances encountered by the patient and family. Therefore, patients and caregivers should be taught self-management and problem-solving skills that will allow them to recognize when adherence is waning, assess the barriers impeding their adherence, and either develop their own management strategies by generalizing from past experiences or seek professional assistance when necessary.

11.5. SUPPORTING STUDIES

In a 2005 study[1] the investigators found that family dysfunction and poor child coping skills were significantly associated with worse adherence.

Therefore, psychotherapy aimed at modifying these problems was recommended for adolescents with chronic inflammatory bowel disease. The investigators observed that families with appropriate rules and consequences for child behavior had children who were more adherent. These authors recognized that adherence in pediatrics is more complex than in adult medicine because the behavior and functioning of both the child and the adult caregiver must be considered, and that their relative contribution to ensuring adherence changes over the course of the child's development. With young children, the adult caregiver is responsible for ensuring that the child takes his or her medication, but child behavior can thwart adult efforts to give the medication. In adolescents, medication adherence is even more complicated as the adolescent seeks autonomy yet may lack the cognitive and emotional maturity to recognize the importance of consistent adherence. Adolescents may lack the organizational skills and self-discipline to take medication independently in the context of their social world, where they are loath to appear different from their peers. Thus, the ability of families to manage the dynamic tension between the adolescent's drive to gain autonomy and the parents' ultimate responsibility to ensure adherence with prescribed medication is an area in which behavioral therapists and psychologists can make an important difference in support of successful adherence. Given that parents provide the necessary organization and planning needed for children and (to a lesser degree) for adolescents, particular attention should be paid to assisting families who are less structured and organized and lack sound child management and disciplinary skills.[1,13,18] Some early interventions targeting families' abilities to set appropriate rules and consistently implement consequences for behavior problems resulted in improved adherence relative to comparison groups not receiving this intervention.[34–36]

Another approach to behavioral intervention aimed at improving medication adherence in adolescents with cystic fibrosis was to teach youth better problem-solving, communication, and cognitive restructuring skills.[37] One investigator[6] emphasized the importance of conceptualizations that assess barriers to adherence and use the results to design interventions for overcoming these barriers and thereby improving adherence in youth with diabetes. A review of the empirical research literature on diabetes mellitus management in children and adolescents conducted by the same investigator highlighted behavioral interventions that have empirical support, including treatments that target adherence, social skills, coping skills, family

communication and problem solving, anxiety and stress management, and weight control.[6]

In the case of pediatric diabetes, research has shown that the risks of medical complications such as heart disease, kidney failure, blindness, and nerve damage increase in a linear fashion as the patient's long-term blood glucose levels increase. Conversely, if normal blood glucose levels can be maintained, the incidence of these complications falls to the same level as that found in the general population.[6]

It has been said that managing health care–related behavior is the key to effective diabetic control and that the greatest barriers to effective control are behavioral.[6,38–39] It is increasingly well recognized that, given the complexity of maintaining diabetic control, the role of a behavioral specialist on the diabetes care team is critical for children living in families with complex psychosocial problems. One common problem is when caregivers give children too much independent responsibility for their medical self-care tasks. This may be especially likely in families that are stressed by low socioeconomic status, have a single caregiver, or lack social, communication, and coping skills. It has been argued that coping with diabetes management can be facilitated by supportive family and peer relationships, as well as a flexible repertoire of coping and problem-solving skills.[6] In children and adolescents lacking these supports and skills, escape and avoidance behaviors are common. These behaviors include avoiding glucose testing and insulin injections, anxiety about becoming hypoglycemic, and school avoidance because of anxiety about peer perceptions of one's disease and diabetes control regimen. Whatever the specific sources of psychological stress, it can disrupt diabetes control by interfering with regimen adherence and because stress hormones can block the effects of insulin and increase blood glucose levels.[6] Behavioral interventions for improving adherence with diabetic control regimens have targeted the escape/avoidance, anxiety, communication, and coping problems mentioned above, and a variety of behaviorally oriented interventions have been studied and empirically validated. These studies have been reviewed in detail elsewhere,[6,40–41] and the reader is encouraged to read these sources in addition to the summary discussion provided here.

Relatively early studies in this area focused on testing the effects of behavioral contracting and other behavior modification interventions aimed at increasing diabetes regimen adherence. In these interventions behaviorally trained therapists helped children and parents set up and implement

contingency management programs in which the children could earn positive reinforcement for improving specific diabetes management behaviors such as increased frequency of glucose testing and adhering to insulin injection and dietary management guidelines. These types of interventions have been shown to improve adherence and diabetic control in many participants.[42–46]

With the introduction of "smart" blood glucose meters that record every blood test by date, time, and result, studies have been conducted on the relative effects of this type of monitoring alone compared with monitoring supplemented with money as reinforcement for meeting testing goals. One study[47] found that adherence with glucose testing exceeded 80% for the group of patients receiving positive reinforcement in addition to using the meter memory to monitor their adherences. Patients not receiving reinforcement for adherence but using the meter alone ranged between 50% and 60% adherence. Interestingly, both groups showed improved diabetes control when compared with groups utilizing conventional therapy without these interventions.

A series of intervention studies have examined the effects of behavioral interventions conducted in a group format with individual families, multifamily groups, or groups of children/adolescents with diabetes (patients alone). These group interventions have usually targeted coping and/or problem-solving skills thought to affect diabetes self-management. There is research support that a multifamily behavioral parent training intervention aimed at teaching behavioral skills for promoting adherence and diabetic control is effective relative to a standard care comparison group for up to two years post-intervention.[48] Other studies have demonstrated that group coping skills training for adolescents with diabetes can increase diabetes control and improve quality of life.[49]

Many studies have been conducted to determine the effects of family-directed interventions for children with diabetes. One problem that has been consistently noted is a gradual decline in parental involvement with diabetes management as their children get older. This decreasing involvement of parents has been associated with decreasing glycemic control. One group of investigators developed a four-session intervention that was implemented in a diabetes clinic and targeted improving parent-teen sharing of diabetes management responsibilities and reducing family conflict that disrupts such teamwork. Two different intervention groups (teamwork, attention control) were integrated into regular outpatient visits over 12 months. Measures of diabetes-related family conflict were collected at

baseline and after 12 months. Glycemic control was assessed for an additional 12 months for both groups (24-month follow-up). The results indicated that parent involvement in diabetes management can be strengthened through a low-intensity intervention integrated into regular follow-up diabetes care. Although the teamwork intervention increased engagement between the teenagers and parents about diabetes care, families in the teamwork group evidenced decreased diabetes-related family conflict, and an analysis of glycemic control (HbA1c over the 12- to 24-month follow-up period) revealed that more adolescents in the teamwork group (68%) than in the comparison group (47%) improved their glycemic control. These findings support the value of a parent-adolescent partnership in implementing diabetes care and managing chronic disease.[50]

Another variation on this type of group intervention has been the application of a Behavioral Family Systems Model, which has proven effective for reducing general and diabetes-related family conflict and improving observed family communication and problem-solving skills. For patients with poor diabetic control, this type of intervention can produce significant improvements (decreased blood levels of hemoglobin HbA1c) and may improve family interactions and regimen adherence.[51-52]

Multisystemic Therapy is an intensive home-based treatment approach that uses behavioral methods to modify variables in the child's life with regard to interaction with family, peers, school personnel, and the medical team. This approach can improve adherence to blood glucose testing, increase metabolic control, and decrease the number of inpatient hospital admissions.[53-54]

Studies also have targeted disease-specific social and coping skills in children and adolescents with diabetes. For example, the participants may be taught disease-specific assertiveness skills through role playing and rehearsal to respond in more effective and adaptive ways to peer interactions that negatively impact diabetes self-management (e.g., teasing, offers of high-sugar snacks). These studies have been consistently effective at improving the targeted social behaviors[55] and in some studies have significantly improved glycemic control.[56]

Given that glycemic control is influenced by a youth's social context, some researchers have provided training to the peers of patients with diabetes. In this training, the peers learned to exhibit behavior that their friend with diabetes had affirmed as supportive and helpful in promoting successful diabetes self-management.[57] Overall, within the pediatric diabetes self-management literature, behavioral contracting and behaviorally

based family interventions have consistent empirical support for the treatment of adherence with diabetes regimens.[6]

A recent study[58] conducted a meta-analysis of interventions aimed at adherence promotion in pediatric patients with type 1 diabetes. To be included in this meta-analysis, a study needed to meet the following criteria: (1) was a randomized controlled trial (RCT), (2) studied patients less than 19 years of age, (3) studied youth with type 1 diabetes, (4) reported data on glycemic control, and (5) provided adherence- or self-management-promoting intervention components. Results from the 15 studies that met those criteria were used in the analysis and represented a combined sample of 997 youth. The results of the meta-analysis indicated that improvements in glycemic control were modest overall. However, those targeting emotional, social, or family functioning in support of diabetes control were more effective than those aimed at increasing a specific individual behavior such as increasing the frequency of blood glucose testing. This supports the assertion that to be most successful, behavioral interventions need to consider the psychosocial and emotional context in which the patient lives.

Another population in which medication adherence has been studied is youth with ADHD who have been prescribed psychostimulant medication. Although pharmacological interventions for ADHD have been in use for decades, interventions targeting medication adherence in this group have rarely been conducted. The investigation of adherence in this group has been a subject of interest only relatively recently, and research in this area has focused on identifying variables associated with better adherence, but not on specific interventions to attempt to improve medication adherence.[59] The lack of intervention research on improving medication adherence in this group is surprising. Other research suggests that only about half of patients with ADHD take their medication as prescribed and that half of parents overestimate their child's medication adherence. This nonadherence is especially troublesome when children are only receiving pharmacological treatment for their ADHD in the absence of systematic behavioral treatment. More attention to empirically validating techniques for enhancing medication adherence in this group is needed.[7]

Another systematic review of the research literature[60] located controlled clinical trials that attempted to improve medication adherence to long-term medication in youth that were 18 years of age or younger and had a chronic illness. Seventeen studies were included in the review. Seven of the studies implemented educational strategies alone, seven involved behavioral inter-

ventions, and three used educational intervention combined with other psychological therapies. The results of this review indicated that educational interventions alone are generally insufficient to promote better adherence (two out of seven studies showed benefits). Behavioral interventions tend to be more effective (four out of seven studies supported benefits of behavioral interventions), and combining education and behavioral intervention appears to be more effective than education alone. However, studies combining education with other non-medication-specific psychological interventions had no beneficial effect on medication adherence. It is informative to note that in these studies education typically involved providing verbal or written information about the nature of the patient's illness, the rationale for treatment, and the benefits of medication adherence. The behavioral interventions included monitoring, goal setting, reinforcing medication ingestion with tangible rewards, contingency contracting, problem solving, and linking medication taking to established routines such as meals, school, and bedtime. Interestingly, this analysis did not find any clear relationship between intensity or duration of intervention and degree of adherence.[60]

11.6. CLINICAL CASE EXAMPLES

The following case studies were included in a professional conference presentation in 2005;[23] they are summarized here to illustrate the usefulness of operationalizing and assessing for barriers to adherence in order to develop barrier-specific clinical interventions.

Case Example 1—"Corin": Treatment of Child Escape/Avoidance Behavior

For "Corin," a 4-year-old female with HIV and ADHD, the specific child barriers identified during clinical assessment were conditioned nausea (and gagging) and behavioral escape avoidance (physical avoidance/disruption) requiring physical restraint (manual guidance for escape prevention to administer her antiretroviral medication). With implementation of the intervention by behavioral therapists and nursing staff (masking of medication taste, differential reinforcement for medication acceptance and swallowing, and contingent restraint for disruptive behavior and to prevent escape), target disruptive behaviors were decreased (fig. 11.1, lower panel), and 100% compliance was achieved, resulting in significant reduction

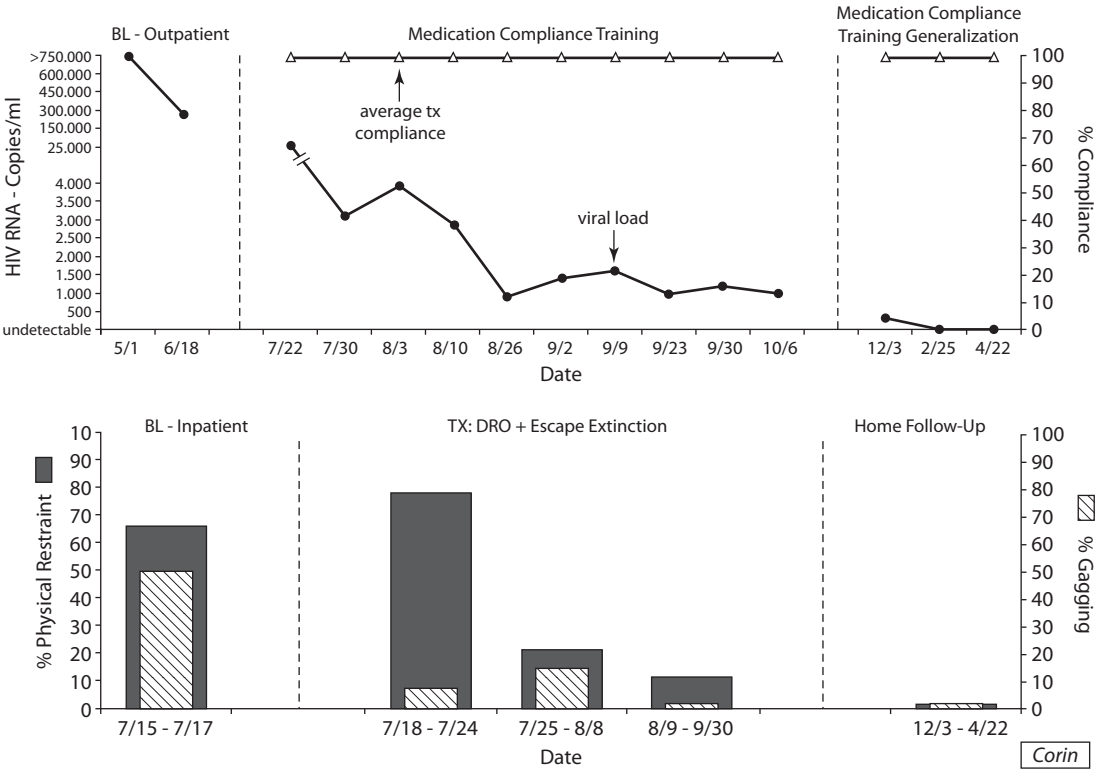

Figure 11.1 Clinical outcome data for "Corin" displaying viral load (*top panel, filled circles*), percentage of medication acceptance (*top panel, open triangles*), percentage of medication presentations requiring physical restraint (*bottom panel, black vertical bars*), and percentage of presentations with gagging (bottom panel, striped vertical bars) across baseline, intervention, and generalization phases. Reproduced with permission from Amari, A., Beck, M., Piszczor, R., Wertalik, G., & Slifer, K.J. (2004). Assessment of barriers to medication compliance in pediatric HIV patients: A pediatric psychology consultation clinic review of cases. Society for Pediatric Psychology, APA Division 54, National Conference on Child Health Psychology, Charleston, SC.

in viral load, from admission count of >750,000 to discharge count of 994, and undetectable at outpatient follow-up (fig. 11.1, upper panel). Intensive caregiver education and training were provided on an inpatient and outpatient basis to increase understanding, supervision, and use of a structured routine and behavioral contingencies. During the four months of home implementation, the need for contingent restraint (manual guidance for escape prevention) was decreased to near zero.

Case Example 2—"Rob": Treatment for Adolescent Coping

For "Rob," a 14-year-old male, the specific barriers identified during clinical assessment included conditioned nausea, anticipatory anxiety, and "not wanting others to know." Inpatient admission resulted in 100% compliance with behavioral therapists and nursing staff implementation of intervention (masking medication taste, relaxation/distraction during administration, structured self-monitoring routine with supervision and reinforcement, and individual supportive therapy for overall coping). Intervention resulted in adolescent self-reported decreases in anticipatory anxiety/nausea, increased medication acceptance, and documented decreases in viral load from admission count of >750,000 to discharge count of 1,400 and undetectable at follow-up (fig. 11.2). Caregiver education and training were provided on an inpatient and brief outpatient basis to increase caregiver understanding, supervision, and use of a structured routine and behavioral contingencies.

Results of this type highlight the need to redefine and operationalize medical nonadherence in terms that are less global and judgmental and more useful for clinical intervention.[23] These types of clinical cases and outcomes serve to illustrate that nonadherence is not one "thing" or behavior, but often is a constellation of complex and interwoven variables requiring identification and specific intervention.

KEY CONCEPTS

- The behavioral and environmental variables that influence medical adherence are similar across many medical conditions and regimens.
- At younger ages adherence is largely a function of parent behavior and their ability to understand the importance of the regimen and to manage their child's daily schedule and behavior.

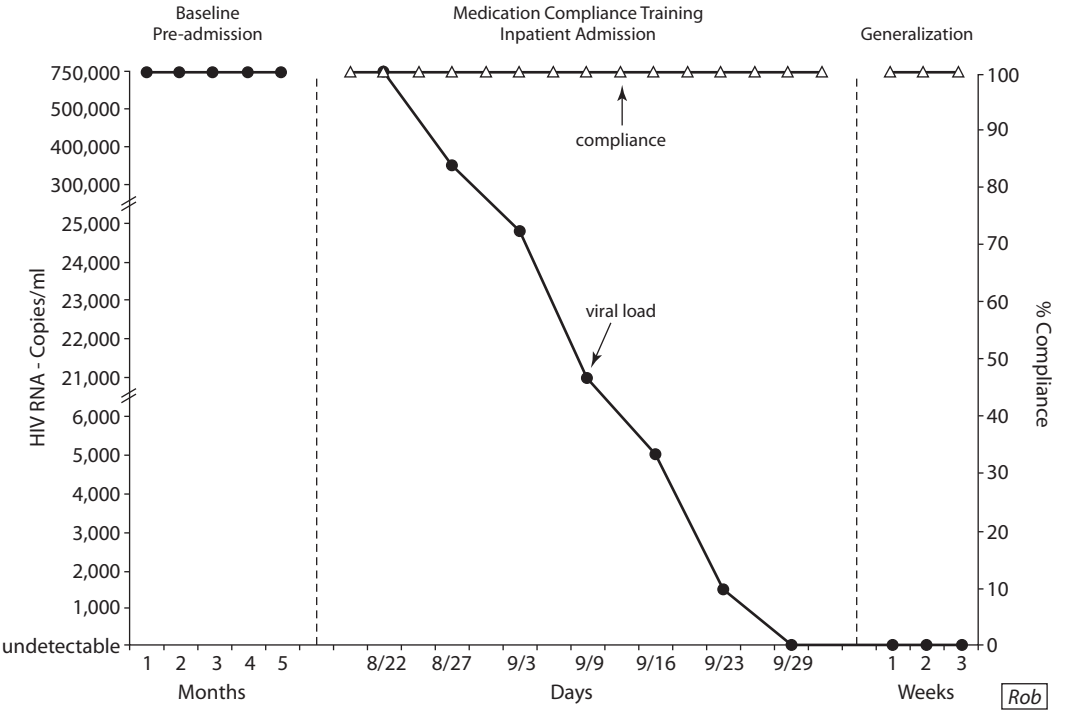

Figure 11.2 Clinical outcome data for "Rob" displaying viral load (*filled circles*) and percentage of medication acceptance (*open triangles*) across baseline, intervention, and generalization phases. Reproduced with permission from Amari, A., Beck, M., Piszczor, R., Wertalik, G., & Slifer, K.J. (2004). Assessment of barriers to medication compliance in pediatric HIV patients: A pediatric psychology consultation clinic review of cases. Society for Pediatric Psychology, APA Division 54, National Conference on Child Health Psychology, Charleston, SC.

- Adherence tends to be an increasing problem during the adolescent years, when parents begin to transfer responsibility for adherence to the adolescent and to decrease their own oversight.
- Medication adherence is complicated when adolescents seek autonomy but lack organizational skills and the cognitive and emotional maturity to recognize the importance of consistent adherence.
- Research supports the value of a parent-adolescent partnership for medical adherence and managing chronic disease.
- Adherence is often lowest when symptoms are in remission or well managed, the child is feeling well, and medication is taken to maintain health rather than to treat active, distressing symptoms.
- Research suggests that parent and child reports tend to overestimate adherence.
- The simplest and most practical approach to measuring adherence is to combine assessment methods such as semistructured telephone interviews, pill counts, and pharmacy refill records.
- Families with appropriate rules and consequences for child behavior tend to have children who are more adherent with their medical regimen.
- Educational interventions alone are generally insufficient to promote better adherence, but behavioral intervention alone or combined with education tends to be more effective.
- Successful behavioral interventions for adherence have included self-monitoring, goal setting, reinforcing medication ingestion with tangible rewards, contingency contracting, problem solving, and linking medication schedules to established routines such as meals, school, and bedtime.
- To be most successful, behavioral interventions need to consider the psychosocial and emotional context in which the patient lives.
- The application of a Behavioral Family Systems Model has been effective for reducing adherence-related family conflict and improving family communication, interaction, problem solving, and regimen adherence.

- Within the pediatric diabetes literature, behavioral contracting and behaviorally based family interventions have consistent empirical support for improving regimen adherence.

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Teaching Children with Chronic Medical Conditions to Cope with Repeated Needle Sticks and Other Painful Procedures

IN THIS CHAPTER

- Children with chronic medical conditions often develop severe conditioned anxiety and an elaborate repertoire of behaviors that allow them to delay or escape medical procedures.
- This chapter reviews the research literature on behavioral and psychological interventions for treating medical procedure-related conditioned anxiety/distress and related escape/avoidance-motivated behavior in children.
- The learning and conditioning principles that are thought to underlie the development of conditioned anxiety and related disruptive escape/avoidance behavior are presented.
- Behavioral recommendations for modifying conditioned anxiety and escape/avoidance-motivated behavior are provided.
- Tactics are suggested for integrating behavioral interventions with topical anesthetic and/or other medical pain management approaches.

12.1. PATIENT POPULATION AND TARGET PROBLEM(S)

This chapter addresses the specific needs of children of all ages who have chronic or recurrent medical conditions that require them to cooperate and cope with repeated painful medical procedures such as blood tests, injections, and placement of intravenous lines (IVs). Chapter 6 focused on the unique experiences and vulnerabilities of young children from infancy

through school entry when they encounter routine immunizations or other commonly experienced, but low-frequency, painful procedures. The current chapter elaborates on the difficulties of children with chronic medical conditions who must undergo frequent painful procedures. Many children with chronic illnesses require repeated medical procedures, which can be painful despite pharmacological interventions for pain management.[1] From the child's point of view, the aversive stimulation is intermittent, unpredictable, and uncontrollable. Under these conditions, a variety of negative behavior patterns can develop, including conditioned anxiety, withdrawal, attempts to avoid or escape medical stimuli, and, in some cases, severe tantrums or aggression.[2–5] Procedure-related behavioral distress is particularly a problem for toddlers and preschool-age children.[4,6] Children with cancer have reported painful procedures to be the worst part of their medical treatment. Furthermore, they do not reliably habituate to repeated painful procedures.[6–7] Highly invasive procedures such as lumbar puncture (LP), bone marrow aspiration (BMA), and wound cleaning tend to be the most painful procedures and are often performed under sedation or general anesthesia.[1,4,8] However, there are a number of other painful and often-repeated procedures such as IV placement, venipuncture (phlebotomy or blood drawing), subcutaneous (SQ; under the skin) injections, and intramuscular (IM; into the muscle beneath the skin) injections. All of these procedures are a major source of pain, distress, and apprehension for children.[9–12]

Severe procedure-related behavioral distress from even minor painful procedures is often managed with sedation, physical restraint, and, if necessary, general anesthesia. Anesthesia, sedation, and restraint can both increase the risks associated with medical care and significantly impact a child's quality of life.[13] Fortunately, behavioral and cognitive-behavioral therapies can provide relief from procedural pain, distress, and anxiety when used alone or combined with pharmacological interventions.[14]

Noncompliance with needle procedures is particularly common among children with developmental disabilities. Such procedures often provoke severe distress due to anxiety about anticipated pain and unfamiliar equipment, difficulty inhibiting movement, and hypersensitivity to the sensation of touch. Children with intellectual and developmental disabilities (IDD) are likely to undergo needle procedures frequently because of associated medical conditions, but they also have more difficulty tolerating the procedures due to their disabilities. Often, attempts are made to address this problem by employing restraint, sedation, or anesthesia. However, restraint is

traumatic for children and caregivers. Sedation is often unsuccessful in children with neurological or developmental disorders and may have unwanted side effects such as vomiting and prolonged post-procedure sleepiness. This chapter focuses on alternatives to sedation, anesthesia, or restraint for ensuring child cooperation with painful medical procedures.

12.2. ASSESSMENT AND MEASUREMENT

As introduced in chapter 3, a task analysis refers to breaking a complex behavior to be performed or a task to be learned into component steps so that they can be presented to the patient one step at a time. As each step is presented, the therapist or an objective observer can then document how many of the steps the patient can complete based on direct observation. The patient's specific behavioral response to each step and the level of prompting required can be recorded for each step. Specifically, the therapist or observer can easily note the level of prompting given (verbal, modeling, physical guidance) for each step along with whether or not the patient performed the step or allowed it to be performed. In addition, the occurrence or not of negative vocalizations (crying, moaning, screaming, or verbal statements asking or telling the therapist to stop, get away, etc.) can be recorded along with the occurrence of any disruptive behavior. These data can be recorded in this way for all sessions across baseline (before treatment) during treatment and at follow-up visits. The data can be calculated in terms of the number or percentage of steps during which the specified behavior was observed to occur. These data can be tracked across time (visits, sessions, trials) to document behavior change as a result of the behavioral intervention(s) provided. An example of a task analysis for needle sticks for blood drawing or medication injection employed by the author of this book and colleagues in a recent study[15] is shown in table 12.1. Data acquired and calculated using this method are illustrated in figure 12.1, shown in section 12.7. The task analysis shown below can be easily modified to match other uncomfortable medical procedures. Although there are many other approaches to measuring behavioral distress, they typically require live scoring of directly observed behavior using a portable computer or post-session coding of videotapes recorded during the procedure.

TABLE 12.1 Example Task Analysis for Needle Stick Procedures

Required Step/Behavior	Prompt? Verbal, Model, Guidance	Step Completed?	Negative Vocalization?	Disruptive Escape or Avoidance Behavior?
Sit in chair and begin watching DVD				
Place arm in position				
Adjust clothing to expose site				
Put on gloves				
Touch/probe site				
Tie tourniquet on upper arm				
Apply alcohol				
Prepare mock needle (0/4, 1/4, 1/2, 3/4, 4/4) circle needle size				
Apply mock needle (0/4, 1/4, 1/2, 3/4, 4/4) circle needle size				
Hold in place for 5 seconds				
Hold in place for 10 seconds				
Hold in place for 30 seconds				
Hold in place for 1 minute				
Hold in place for 1.5 minutes				
Hold in place for 2 minutes				
Manipulate tubing/vial with needle in place (if actual needle, *qualified medical staff only*)				
Perform needle stick with real needle (*qualified medical staff only*)				

Source: Slifer, K.J., Hankinson, J.C., Zettler, M.A., et al. (2011). Distraction, exposure therapy, counterconditioning and topical anesthetic for acute pain management during needle sticks in children with intellectual and developmental disabilities. *Clinical Pediatrics, 50*, 688–697. Reprinted with permission from Sage.

12.3. CONSIDERATIONS FOR FAMILY CAREGIVERS AND HEALTH CARE PROVIDERS

Working with children with chronic illness can be emotionally difficult for all types of caregivers, even those who work with children with cancer, diabetes, or other life-threatening conditions on a daily basis. It can be especially challenging to know that the procedure one is performing causes a child to experience pain and distress and the family to feel anxiety and helplessness. It is also possible to become numb to a child's distress during such procedures if you are performing them daily. Behavioral assessment and intervention with children receiving painful procedures must be discussed and coordinated with the treating physician(s) and other health care staff such as nurses and phlebotomists (medical laboratory staff who draw blood or do blood tests). Knowing that the physician regards the painful procedure and the behavioral intervention plan to be both medically indicated and safe can be reassuring to nonmedical family caregivers.

Behavioral therapists working with children undergoing painful procedures cooperate closely and, when indicated, provide co-treatment with medical, nursing, or laboratory staff present, especially in the early phases of assessment and testing intervention strategies. A collaborative team effort that includes careful communication and coordination among medical, behavioral, nursing, laboratory, and family caregivers is essential. If you are not in a setting where this level of collaboration is possible, it would be unwise to attempt to intervene during painful procedures unless the family caregivers are especially motivated and the primary care physician is completely in support of attempting to decrease the child's distress through behavioral intervention. Otherwise, the behavior therapist may be perceived to be intrusive, unhelpful, and causing a painful but routine procedure to take longer than necessary.

As discussed in chapter 6, no one likes to think of themselves as someone who hurts or upsets children, but nurses, pediatricians, and medical laboratory staff are regularly required to do so, and family caregivers must allow it to happen repeatedly when children get blood tests, injections, or IVs. It helps to be reminded that this brief pain serves the positive purpose of helping to treat a health- or even life-threatening disease.

Another way for care providers to feel better about causing pain is to decide, as a practitioner, what pain and distress management intervention strategies you will adopt in your practice and, as family caregivers, what

interventions you will request and help to implement with your child. By adopting and consistently implementing a set of procedures supported by the research literature, one can know that appropriate and reasonable steps were taken to minimize the hurt and avoid emotional trauma. The list that follows provides some common examples of strategies that have been helpful in clinical practice for managing child distress during needle procedures.

It is especially important for parents or other family caregivers to realize that they can be helpful in different ways in different situations. For example, if the child needs an emergency procedure, the best thing the caregiver can do is to be present and comforting to the child before and after the procedure, but to stay out of the way during the procedure. On the other hand, if the procedure is elective, such as a routine blood test, the caregiver can be a good advocate who communicates to the medical staff what their expectations are for the use of distress and behavior management strategies during the procedure and what limits will be placed on how the child is treated. Such expectations and limits should be stated up front in a firm but polite manner.

PROCEDURES THAT MEDICAL STAFF AND FAMILY CAREGIVERS CAN IMPLEMENT TO DECREASE AND MANAGE BEHAVIORAL DISTRESS DURING NEEDLE PROCEDURES

- Plan to use topical anesthetic; have it prescribed and picked up from the pharmacy ahead of time
- Prepare multiple potential needle stick sites in advance with topical anesthetic
- Apply the topical anesthetic in enough time for it to have its best effects when the procedure is performed (e.g., for EMLA cream, 45 minutes ahead of time)
- Keep waiting-room time brief to prevent escalating anticipatory anxiety
- Conduct the procedure in a dedicated area or procedure room to keep all other spaces "safe" and pain-free
- Have all necessary medical supplies prepared and out of the child's immediate view before having the child enter the procedure room
- Allow the child to select a preferred activity or prize that will be awarded after the procedure is finished

- For blood tests, prior to beginning the procedure, establish with the phlebotomist or nurse that if the lab results are not urgently needed and the initial needle stick misses, the phlebotomist will not manipulate the needle under the skin in an attempt to find the vein
- Agree that a needle that misses will be withdrawn, the child will have a chance to recover emotionally, and then another stick will be performed at a different body location that also has been prepared with topical anesthetic
- Establish that the child will be subjected to no more than an agreed-upon number of sticks (e.g., no more than two) and, if unsuccessful, the blood draw or injection will be rescheduled
- Provide developmentally appropriate interactive toys for distraction before, during, and after the procedure (allow the child to select from a limited number of choices)
- Direct and continue to redirect the child's attention to the distraction activity (e.g., handheld computer game, toy, push-button book, iPad, smart toy, or smartphone) during the procedure and quietly praise or otherwise reinforce performing the distracting activity
- Provide quiet praise and a small reward (access to a preferred toy or activity, an edible treat, or a visit with a favorite person) afterward for cooperation and coping with the procedure, even if the child cried or yelled
- Praise the child for making it through a difficult situation and for calming down and resuming everyday activities

It also is helpful to know when a child and parent may need professional behavioral or psychological services. The child may be distressed to a greater degree and for a longer time than children his or her age typically are during the same or similar procedures. The child may attempt to avoid or escape the injection by pushing away or hitting. A parent might scold, bargain with the child, and repeatedly allow the child to avoid the procedure. Some parents apologize repeatedly to the child. These difficulties are likely to be observed on multiple occasions in children who require repeated painful medical procedures. It is appropriate to suggest and provide referral information to the family caregiver for a behavior analyst or behaviorally trained pediatric psychologist.

Whether providing basic preventive procedures in your daily practice or referring a child and family to behavioral professionals for assistance, medical, nursing, and laboratory staff can know that they have gone to some effort to perform blood draws, injections, or other painful procedures as humanely as possible.

12.4. INTERVENTION PROCEDURES

The procedures employed by the author of this book and colleagues in recent work[15] are presented below to provide practical instruction on how to conduct this type of intervention.

During the first session with the behavior therapist, the caregiver is interviewed about the child's prior experience with and behavioral responses during attempts at needle sticks and other challenging medical procedures. Information about the child's preferred activities also should be obtained from the caregivers to identify activities that might be used for distraction, counterconditioning, and positive reinforcement during therapy sessions. For nonverbal children with developmental disabilities a more formal stimulus preference (reinforcer) assessment may be necessary.

To establish a baseline level of cooperation and coping, the therapist should attempt to conduct a mock needle stick procedure. The mock procedure should continue until the level of child distress behavior observed makes it clear that a real needle stick could not be conducted safely (e.g., the child shows interfering, avoidance, or escape behavior). After this level of distress is observed, the attempt to complete the entire mock needle stick should be discontinued. If the child does not become distressed at this level, the entire mock procedure is completed.

When beginning behavioral intervention sessions, hand lotion can be applied to the potential needle sites to simulate application of topical anesthetic for the mock needle sticks.

Behavioral treatment is conducted during mock stick sessions. The mock sticks are implemented using an actual but modified (blunted) "butterfly" needle or injection syringe. The modified butterfly needle or syringe can be created by carefully removing the actual needle and replacing it with a blunt probe such as a piece of paperclip wire that is of comparable length and thickness and not in any way sharp on the tip. When necessary, the mock needle exposure may begin with a butterfly or syringe without a needle of any type. In these cases the mock needle can be faded in one-quarter

length at a time, becoming progressively longer and more salient across sessions as the child is able to tolerate it.

During all mock needle sessions after the initial baseline assessment, relaxing and distracting activities (computer games, electronic smart toys, movies, or idiosyncratic but highly preferred activities) must be provided to establish a positive, relaxed state; motivate approach behavior; and facilitate counterconditioning.

During counterconditioning sessions, the child is provided with and prompted to participate in the distracting, relaxing activity. Such activities are hypothesized to produce an emotional state that is incompatible or at least competes with anxiety and distress (i.e., provides pleasure and relaxation).

Once the child appears to be relaxed and enjoying the activity, he or she is gradually exposed to increasing proximity and duration of exposure to the feared stimulus. While the child is participating in the preferred activity, materials required for a mock blood draw or injection should be introduced gradually, one step at a time, according to a procedural task analysis such as that shown in table 12.1, and at an individualized pace that allows progression with a minimum of child distress behavior.

The gradual introduction of medical materials is conceptualized as a form of stimulus fading, which involves gradually changing one or more features of the "needle" stimulus (length, thickness, proximity) without significantly altering the child's behavior. For example, when the child is comfortably playing, a tourniquet might be loosely draped over his or her forearm, and then this stimulus can be faded by tying it loosely around the same arm, and thereafter making the tourniquet incrementally tighter. If fading progresses at an appropriate pace, the child's behavior should not change significantly even though the stimulus has gradually changed.

Concurrent with stimulus fading, positive reinforcers such as praise, edibles, and stickers which are highly preferred by the child should be provided contingent on approximations of cooperative behavior.

Also concurrent with the stimulus-fading and differential positive reinforcement procedures, any avoidance or escape behavior that occurs must be placed on operant escape extinction by ignoring, blocking, or redirecting it. More specifically, escape extinction must prevent escape behavior (running away, pushing, or turning away from the mock medical stimuli) from being successful at interrupting or terminating the planned stimulus exposure during the mock procedure. Escape behavior can be placed on

extinction by interrupting or preventing it using verbal prompting, redirection to a specific alternative activity or task, and, if necessary, physically blocking while gently guiding the child to remain in the situation. By blocking escape behavior, the therapist is able to weaken and eventually extinguish the association between the feared/nonpreferred stimulus and behavior that had previously allowed the child to avoid or escape it.

After the child can tolerate a mock needle stick procedure conducted by one or more behavior therapists without distress, a nurse or phlebotomist (medical laboratory technician) can be introduced to the mock procedure to learn and assist with the behavioral routine.

Ideally, any caregivers and medical staff who will be involved in the actual needle stick procedure should be provided behavioral training to increase the consistency with which these individuals interact with the child during the procedure. During each training session, the behavior therapist demonstrates appropriate verbal interactions, differential reinforcement, and escape extinction techniques for the caregivers. Ultimately, this information should be carefully reviewed and demonstrated during a brief preparatory meeting with the medical personnel who will conduct the actual needle stick.

The same or similar preferred activities or objects used during behavioral training sessions should be provided during the actual needle stick procedures.

It is recommended that the child be prepared with a topical anesthetic such as EMLA (Astra Pharmaceutical Products, Inc., Westborough, MA) applied to his or her potential needle stick site(s) 30–45 minutes prior to the actual needle procedure. The physician who ordered the needle procedure should be asked in advance to prescribe the topical anesthetic, which the caregiver can then obtain from a pharmacy and apply before leaving home or upon arrival at the clinic or blood test facility.

Medical staff members should be asked to have all necessary medical materials ready and available but out of the child's line of sight before bringing the child into the treatment room. Requiring the child to wait in a treatment room while the nurse or phlebotomist collects necessary materials must be avoided because this may increase child distress and frustration, if the waiting period is too long and unstructured.

Ideally, the behavior therapist who conducted the counterconditioning sessions should be available to collaborate with the nurse or phlebotomist to implement the behavioral routine during the actual needle procedure.

The nurse or phlebotomist should be asked to first conduct a mock procedure and then, if the child has been cooperative, proceed with the actual needle stick.

If the behavior therapist cannot be available during the actual needle stick procedure, the family caregiver who brings the child for behavioral training sessions and will be present during the actual procedure should be taught to perform the behavior therapist's role as a collaborator with medical staff and a coach to the child. This involves learning to prompt the child to engage in the distracting activity, preventing avoidance or escape behavior, and positively reinforcing child cooperation and coping.

While these procedures have been quite successful in research and clinical experience, they are not successful 100% of the time for all children. Therefore, if the child is unsuccessful at cooperating during the actual needle stick procedure (whether the procedure ultimately is completed with physical guidance by medical staff or not), he or she should be kept in the procedure area until calm and once again distracted by a preferred activity in order to avoid negatively reinforcing any uncooperative or distress behavior with contingent escape from a nonpreferred environment.

While a failed procedure attempt is disappointing, it does not preclude continuing with behavioral therapy sessions as soon as possible and scheduling another actual procedure when the child is once again fully cooperative and calm during the mock training procedures.

In some cases, it may be helpful to combine an antianxiety medication such as Valium or Ativan during the actual needle procedure with the behavioral training described above. Of course, this needs to be planned with and prescribed by the child's physician(s) and ideally should not be used unless the child's reaction to the medication has been tested ahead of time (possibly during a mock needle procedure session). If use of this medication leads to a successful actual needle procedure, it should be continued for subsequent procedures along with the behavioral intervention, and under the physician's supervision the dosage may be faded over time and eventually discontinued.

Representative data for three children who were treated using the behavioral intervention discussed above are presented in section 12.7.

12.5. SPECIAL CONSIDERATIONS AND CHALLENGES

Although the interventions discussed above have been used successfully in many cases, the children and families were required to be available for

repeated sessions over several weeks, which may be prohibitive for some families. Repeated sessions are required for children with IDD and/or severe conditioned behavioral distress to have sufficient time to learn cooperative behavior under safe conditions. Repeated sessions are needed to gradually expose the child to previously distressing stimuli (conditioned aversive stimuli) in order to counteract the conditioned distress, arousal, and escape/avoidance behavior that has become associated with those stimuli. Due to the requirement for repeated sessions, this intervention is relatively costly and time-consuming, but teaching children with chronic health conditions (with or without IDD) to cooperate and cope with painful medical procedures that they will experience throughout their lifetime is a worthwhile investment.

It should be noted that counterconditioning and many other learning-based behavioral interventions are not suitable for emergency or urgent care needle sticks. Under these circumstances, basic trauma prevention strategies, including distraction and provision of tangible positive reinforcement contingent on procedure completion, may be helpful. However, depending on the child's medical condition, level of illness- or injury-related pain, and the urgency for test results or immediate treatment, sedation or anesthesia may be the most appropriate alternative.

Providing the types of behavioral services described in this chapter can be more challenging with toddlers and preschool-age children, as well as children of any age with severe IDD. Very young children and those with severe anxiety or behavior problems that occur across settings will need more intensive and frequent behavioral training and an experienced behavior therapist. For these more severely affected children, the behavior therapist may have to manage severely disruptive and dangerous behavior that is motivated to escape nonpreferred or painful medical situations. In such cases, learning may be slower, more training trials may be required, and more barriers to safety and success may exist. In these situations the availability of colleagues for backup is critical. Sometimes two or more behavior therapists may be necessary to block and redirect disruptive, unsafe behavior and to implement the exposure, counterconditioning, and differential reinforcement-based procedures. Intervention sessions may need to be brief and frequently repeated, and an especially controlled environment may be required to keep an aggressive, self-injurious child safe while waiting out a tantrum when implementing an extinction-based procedure. Some children who are highly inattentive and escape motivated may learn more quickly if training is conducted in brief trials in one setting

and then the child is allowed to escape the "work" setting for a break in a "play" setting" after he or she was cooperative during the preceding training trial.

Children with autism or related disorders may be highly sensitive to changes in routine and some types of sensory stimulation (touch, unexpected noises, etc.). In all of these situations more time, patience, resources, planning, problem solving, and access to the patient and family will be necessary. Especially difficult cases will require referral to behavior analysts who work in a highly specialized setting that has intensive medical and behavioral resources. Such facilities are relatively rare but are most likely to be available at university-affiliated hospitals. Such programs might be referred to as behavioral medicine programs and may be imbedded in departments of pediatrics or psychiatry at major medical institutions.

The difficulty and complexity of working with children and youth with severe behavioral and developmental disorders require that the reader is conscious of his or her own capabilities, limitations, and resources before attempting to intervene to facilitate cooperation and coping during painful medical procedures.

12.6. SUPPORTING STUDIES

Variety of Interventions and General Findings

Over the past few decades, the format of behavioral interventions has varied and included filmed modeling, relaxation, visual imagery, hypnosis, and distraction. Typically, children and caregivers are provided with training sessions in the clinic and may be coached by a therapist, nurse, or child life specialist during painful procedures.[2,4,16–23] Many early studies emphasized the importance of "sensory information," allowing the child to experience as many as possible of the visual, auditory, tactile, and olfactory stimuli involved in the procedure they would be undergoing. Through exposure to the relevant medical stimuli during demonstrations, role playing, and filmed or live modeling, children learn what to expect during the upcoming procedure.[4,17,20] Research also has shown that the benefits of exposure to sensory information can be strengthened by rehearsing behavior necessary for cooperation and coping during the medical procedure.[4,16–17,23] However, exposure to sensory information may be less helpful to "experienced" children who have already undergone the painful procedure and have developed conditioned anxiety and avoidance.[24–27] Behavioral and

cognitive-behavioral interventions such as controlled breathing, progressive muscle relaxation, visual imagery, hypnosis, and distraction all have been used alone, in combination, and as an adjunct to pharmacological management during procedures such as venipuncture and injections,[1,23,28,29,30] dental treatment,[31-32] chemotherapy,[4,33] LP and BMA,[8,21,34] cardiac catheterization,[35] and gynecological examinations.[36-37]

Recently, the literature was systematically reviewed for randomized controlled trials (RCTs) that compared a psychological intervention group with a control or comparison group.[38] These investigators identified 28 RCTs (with a combined 1,951 participants) that were of sufficient quality for their analysis. These studies generally involved needle procedures for immunizations and injections. The analysis computed standardized mean differences with 95% confidence intervals to compare effect sizes across RCTs. The largest effect sizes for treatment improvements compared with control conditions were for distraction, hypnosis, and combined cognitive-behavioral interventions.[38]

Distraction

Distraction interventions of many different types have been used to divert the child's attention from the procedure and its sensations and thereby decrease the child's behavioral distress.[14] The distraction techniques that have been studied and shown to be successful include music,[29] counting objects in the room,[39] deep-breathing exercises,[39-40] blowing on a party favor, [7,16] nonmedical conversation, toys, puppets, books, bubbles,[16] videotaped cartoons, movies,[1,42] video games,[43] smart toys,[44] a choice of several distracting activities,[45] and virtual reality.[46-47]

It is hypothesized that distraction can produce pain reduction because pain perception is not a fully automatic process, and attention must be directed toward the painful stimulus in order for it to cause distress. Given that cognitive processing capacity is limited, if another sensation or activity competes enough with a painful stimulus, one's perception of it as painful may be altered.[48-49] This theory is supported by recent neuroscience investigations using advanced brain imaging techniques (positron emission tomography [PET] or functional magnetic resonance imaging [fMRI]) to measure pain-related brain activation. The results of such studies demonstrated reductions in activation of the physical sensation areas of the brain (periaqueductal gray matter/midbrain) when participants were distracted by performing a maze task while experiencing experimentally induced

pain such as that induced by the cold pressor pain test.[50] Other studies also have shown modulation of pain-related brain activation by distracting tasks,[51] a verbal attention task,[52] or a cognitively demanding task such as the Stroop test.[53]

Reviews of distraction interventions with children report mixed findings, with no consensus emerging regarding the most effective distraction techniques to employ during specific procedures or with children of specific ages.[14,22,54–55] Many of these distraction techniques have been used in conjunction with parental prompts and/or some sort of reward for cooperation or for using the distracting activity.[54]

Parental coaching may increase some children's use of distraction but also may increase child distress in some preschool-age children.[56–57] In some other studies nurses were trained to function as coaches, and the combination of movie distraction and nurse coaching increased child coping and decreased child distress during painful procedures.[1,42] However, even when coaching by a nurse or therapist is combined with distraction, the beneficial effects may not be maintained across repeated procedures. One study[32] found that use of a poster and audiotaped stories produced only temporary reductions in the disruptive behavior of 4- to 7-year-olds during dental treatments. In another study[23] four children (ages 3–5) and their parents were observed during 7–15 injections across baseline, intervention, and maintenance phases. The children were taught to perform coping behaviors (e.g., playing with toys, puzzles, party blowers, or dolls) in anticipation of injections and to use breathing or counting exercises for distraction during the injections, and parents were taught to coach the child to perform these behaviors. As a result of this intervention, the parents increased their coaching, the children increased their engagement with the distracting activities, and the children's behavioral distress decreased compared to baseline. Unfortunately, improvements were not consistently maintained, and the children continued to be intermittently distressed. Other investigators[16] taught parents to coach their children to use nonprocedural talk when anticipating an LP or BMA and to blow on a party favor or to play with distracting toys during the painful parts of these procedures. These interventions reduced the behavioral distress of three children between ages 4 and 7, but maintenance of these benefits also was variable in this study. On the other hand, in another study[41] videotaped cartoons and a star chart feedback program reduced observed pain behavior, as well as physical therapists' and mothers' ratings of pain, in two girls (ages 4 and 6) receiving hydrotherapy for burns. The benefits

of this combined intervention were maintained across 9 and 22 therapy sessions, respectively. The authors reported anecdotally in their discussion that they had pilot-tested movie distraction alone with three other children undergoing burn treatment, and only "slight" decreases in pain behavior were observed. For some, this may raise the question of whether the two children experienced decreased pain perception or simply learned to suppress pain behavior in order to earn positive reinforcement.

Interactive Distraction

It has been hypothesized[17] that the ideal form of distraction is an activity requiring enough attention to compete with a painful stimulus for a child's attention. Such a distraction intervention should engage multiple senses (i.e., visual, auditory, kinesthetic) and should require active participation involving both information processing and motor responding. Consistent with this conceptualization, video games have been provided to children during chemotherapy and have decreased self-reported and observed distress both before and during chemotherapy and have decreased some children's experience of negative side effects such as nausea, dizziness, and chills. For example, in one study[43] a single-participant experimental design was used to demonstrate the benefits of making video games available to three adolescent boys (ages 11–17) during chemotherapy infusion. The results indicated that, compared with baseline without video games, playing video games decreased the number of anticipatory symptoms reported by the patients, as well as the number observed by the investigators. The video games also reduced the severity of self-reported side effects of chemotherapy. In a similar investigation,[27] the investigators provided a choice from a variety of commercially available video games (with earphones and a joystick controller) to 13 pediatric patients (ages 9–18) receiving chemotherapy. When compared with a control group of 13 children who were given access to toys, books, games, and television but not video games during their chemotherapy, the video game group gave significantly lower self-ratings of chemotherapy-related nausea. In a follow-up study with 15 of the original 26 participants, video games were alternated with control activities for all of the participants on the same occasion using an A-B-A-B withdrawal and repeated-measures experimental design. Again providing the video games consistently resulted in significant reductions in patient-reported nausea.

Another study[58] tested a distraction intervention using electronic smart toys, which could be varied along different stimulus dimensions

and required a physical response. The toy included picture panels that could be interchanged according to the child's preference. It featured the voice of Mickey Mouse instructing the child to press a picture on the panel. Pressing a picture activated an associated sound. Thirty-nine children with cancer between the ages of 2 and 5 were observed for three or six baseline chemotherapy injections and then were provided the smart toy for distraction during three subsequent chemotherapy injections. Playing with the smart toy resulted in 69% of the children showing at least a 20% reduction in behavioral distress. The benefits of this distraction intervention maintained over the three intervention sessions across approximately eight weeks.

In a related longitudinal study[44] the investigators examined the effects of a similar distraction intervention for children undergoing different types of repeated medical procedures (IM injections, PORT-A-CATH sticks, or IV blood draws) over a series of months. Eight preschool-age children and their parents learned to play with an interactive electronic toy robot during chemotherapy or transfusion injections. Initially, the therapist was present during the procedures and prompted the child to play with the distractor. Over subsequent procedures, the parent was taught to prompt and praise the child for playing with the toy, and the therapist's prompting was eventually withdrawn. The robot toy intervention reduced overt behavioral distress in five of eight children, and of those who improved, three maintained the reduction in behavioral distress over 3–16 weeks.

Virtual Reality

Three-dimensional computer-generated video simulations that are interactive and include visual, auditory, and other physical stimulation have been called "virtual reality" (VR) and appear to be an ideal medium for distraction during painful procedures. The benefits of VR have been investigated with children undergoing experimental pain,[59–60] dental treatment,[46] and burn-wound care.[47]

In a study of 26 5- to 7-year-old children during dental restoration procedures,[46] the impact of VR on the children's behavior was assessed using measures of distress, anxiety, and heart rate. Half of the children were provided VR activities during the first visit and not the second. The other half received VR activities during the second visit only. A significant reduction in heart rate but not distress behavior or anxiety was observed during the VR condition. This was not expected because distraction interventions

have usually reduced anxiety and behavioral distress but had inconsistent effects on physiological measures such as heart rate. These results may have occurred because the measures of behavioral distress and anxiety selected by these authors were atypical. Anxiety was measured by having the child draw a human figure immediately before and immediately after dental treatment. These drawings were later evaluated using an interpretive rating system. Behavioral distress was measured using a rating scale to evaluate videotaped observations, rather than the more reliable approach of coding the video for each 15-second interval using operationally defined behavioral categories.[46]

In a study of two adolescent males (ages 16 and 17) receiving VR for distraction during painful burn-wound care, the participants provided subjective ratings using a 100 mm visual analogue scale to indicate the amount of time they spent thinking about pain during the procedure. Both patients showed large reductions of between 47 and 93 mm when using VR distraction compared to when they used video game distraction. VR distraction also has been used to decrease pain and behavioral distress during IV catheter placement.[61] Unfortunately, the expense, availability, and need for special computer peripherals limit the use of VR for procedural pain intervention. However, given its power to provide highly engaging, multisensory, and varied interactive distraction and the accelerating proliferation of personal electronic devices and associated software applications, it is very likely that VR will be used with greater frequency and variety for distraction during painful procedures in the future.

More research is needed on the variables that support maintenance of effectiveness when distraction is used for repeated painful procedures. One hypothesis about why the effects of simple distraction are not well maintained over time is that the child may lose interest in the distracting stimuli. To be effective, distraction must compete with the child's attention to distressing or painful stimuli. However, how much a stimulus distracts is a function of how new and visually striking it is. Video games and electronic toys can be exchanged often to maintain the child's interest while also automatically prompting interactive responding. They also are inexpensive, portable, and can be matched to the child's age and developmental status.

Memory Reframing

One unusual study used a behavioral intervention that was designed to help children use a thinking strategy called "memory reframing" to cope

with repeated painful procedures.[62] In that study, 55 3- to 18-year-old children with leukemia were randomly assigned to either a memory reframing or a control group. They were studied over three consecutive LPs. Memory reframing required the children to participate in two sessions with a therapist: immediately following the first LP and just before the second LP. During these two sessions, the children discussed their memories of their recent LP with the therapist, who had observed the procedure and now encouraged the children to reevaluate their reactions to the LP. They were reminded of coping procedures they used and how it had helped them. They were assisted in recalling their degree of upset during the past procedure (e.g., the extent to which they cried, screamed, or tried to escape) and were given feedback on inaccuracies in their memories of pain and anxiety. In addition, they were given a fluorescent card with a cartoon picture of a child thinking about his or her LP and helped to write down memories discussed during the intervention session on the back of the card. During their next LP, they were reminded to take their card along into the procedure room as a visual prompt to think about what they had learned during the intervention sessions. The results of the study showed immediate reductions in parent ratings of child distress and child heart rate as indicators of anticipatory anxiety for the children who received the memory reframing intervention. In addition, greater reductions emerged during the third (follow-up) LP for the memory reframing group for both anticipatory and procedural distress based on child report, physician assistant's report, and physiological and direct observation measures. Effect sizes in this study were moderate to large except for the direct observation measures of distress.[62] Although this is a unique intervention with apparent ease of implementation and cost-effectiveness, the direct observation measure results were less compelling, and replication of this study is needed.

Learning and Conditioning Principles Hypothesized to Underlie the Development of Medical Procedure–Related Conditioned Anxiety and Behavioral Distress

A theoretical behavioral analysis of the variables controlling child behavior during painful procedures can be based on the basic literature on aversive control,[63] which can provide information about variables that are known to exacerbate or alleviate the negative behavioral consequences of repeated aversive stimulation. Studies have demonstrated that repeated, response-independent aversive stimulation reliably produces behavior

that is consistent across species.[64–66] One observation that is very reliable is the tendency of animal participants to flinch, run, jump, and climb in an attempt to escape nonpreferred or painful stimulation. When this behavior is successful in terminating the painful stimulation, it is strengthened through negative reinforcement. In addition, features of the environment become associated with the painful stimulus by signaling its onset and thereby become conditioned aversive stimuli. As a result, the participant will learn to escape and avoid these conditioned stimuli. Also, if escape is prevented, other predictable behavior patterns occur. These can include temporarily "freezing" in anticipation of the aversive stimulus. This is a behavior pattern that has been termed "conditioned suppression." Aggression in response to the conditioned aversive stimulus also may occur.[63–67]

During aversive conditioning studies, significant changes in physical measures such as heart rate and blood pressure can occur in response to stimuli that signal that the aversive stimulus is about to occur. These changes have been described as a conditioned emotional response.[68–71] The classical conditioning of an emotional response is one theory for how a child may develop a medical phobia such as a needle or blood injury phobia. Other theories include vicarious or social learning, negative information transmission, and nonassociative (biological preparedness or genetic) theories.[72] Research has clearly shown that very young infants experience pain during invasive medical procedures,[73] and it appears that a classically conditioned stress response develops in early postnatal infants when they receive repeated heel lancing for blood tests while hospitalized in the pediatric intensive care unit.[74]

Three types of environmental manipulations can reduce the negative emotional and behavioral effects of aversive stimulation. First, counterconditioning can be conducted by pairing the aversive stimulus and its antecedents with reinforcement[75] or a competing relaxation response.[76] Second, preceding the aversive stimulus with a signal light and/or tone that remains on during the aversive stimulus can provide discrimination learning. This type of learning results in inhibition of movement ("freezing") in response to the signal and in anticipation of the aversive stimulus.[63,77] A third strategy is to provide an apparatus that can be manipulated by the participant. Reinforcing manipulation of the apparatus strengthens a behavior that competes with and reduces aggression and escape behavior.[63–64,78]

Based on a similar process, counterconditioning is a behavior therapy technique that can reduce conditioned emotional responses.[76,79] Stimuli that are prominent in the environment when individuals experience a

painful event may develop conditioned aversive qualities. For example, if an examination table is associated with a painful procedure, then simply seeing the table may cause conditioned physiological arousal (a conditioned anxiety response) and motivate avoidance of or escape from the table and from being near it. Counterconditioning involves attempting to weaken these conditioned associations using planned stimulus pairing. The environment is arranged to induce relaxation and motivate approach of conditioned stimuli such as the treatment room, examination table, and medical equipment and supplies. Relaxation and approach responses can be established in young children by providing familiar, preferred activities. These activities can be paired with the conditioned stimuli (e.g., the treatment room, exam table, and medical material such as alcohol wipes and syringes), and the child can receive praise and tangible reinforcement for participating in these relaxing and distracting activities in the presence of the medical stimuli without attempting to escape. The exposure to the conditioned aversive stimuli can be conducted gradually, with increasing proximity to the stimuli and duration of exposure to them over time. For counterconditioning to occur, the child must experience exposure to the conditioned stimulus (e.g., treatment room, medical supplies) without experiencing the unconditioned stimulus (e.g., painful needle stick). Thus, such an approach depends on the possibility of exposure without pain, which requires practice sessions with mock medical procedures when no real medical treatment is performed. Furthermore, when the actual procedure is performed, topical anesthetic and/or distraction should be used to make it as pain-free as possible.

Consistent with counterconditioning theory, a group of investigators[34] used a multicomponent treatment to reduce the behavioral distress of five children ages 3–7 undergoing repeated BMAs. Their intervention included modeling, deep breathing, imagery, distraction, and behavioral rehearsal. This treatment package successfully reduced directly observed child behavioral distress. In a subsequent study[8] the same behavioral intervention was compared with preparation with oral Valium or a minimal treatment attention control intervention. The three interventions were provided in a randomized, counterbalanced, repeated-measures design with 56 children ages 3–13 undergoing BMAs. Use of the behavioral treatment package resulted in significantly lower observed behavioral distress, pain ratings, and pulse rate compared with the other two interventions. It is impossible to know which components in the behavioral intervention package were responsible for the beneficial treatment effects observed, but one possible

explanation is that when the children rehearsed deep breathing and imagery skills during practice BMAs, relaxation was induced and reinforced, resulting in counterconditioning and reduction of anxiety and associated escape/avoidance behavior.

In a study conducted by the author of this book and colleagues,[80] young children undergoing invasive medical treatments received a behavior therapy intervention based on counterconditioning. The intervention was used to teach five children to cooperate with different types of invasive procedures (i.e., BMA, LP, tracheostomy care, IV, and finger sticks). Medical stimuli used for these procedures were paired with preferred activities during in vivo exposure to mock medical procedures. For example, topical pressure with a blunt "needle" (one-inch section of a paper clip inserted into a plastic hypodermic syringe) was used to perform mock needle procedures. Differential positive social reinforcement was provided contingent on participation in preferred activities (videotaped movie, computer game, or handheld toys) and cooperation with the mock procedure. Once the child was consistently compliant during the mock procedure, the same routine and techniques were used during the actual procedure. Verbal prompts such as "you are going to feel an 'ouch' now" were used as a signal stimulus for the painful parts of the treatment. This study obtained data on cooperation, escape/avoidance behavior, and negative vocalizations to evaluate the effects of the behavioral intervention. The results were replicated across all five children ages 3–5 and provided preliminary support that counterconditioning in combination with pharmacological pain management (e.g., antianxiety medication, topical anesthetic) can decrease behavioral distress in children experiencing repeated invasive procedures.

Discrimination training requires consistently pairing a signal stimulus with a behavioral or environmental contingency (e.g., positive reinforcement or aversive stimulation). As a result, individuals learn to behave in a specific way when one signal appears and a different way when a different signal appears. A published single-case study[81] demonstrated the effects of discrimination training on a 9-month-old child with lung abnormalities and a tracheostomy. The child had been hospitalized on a neonatal intensive care unit from birth and received frequent invasive treatments, including nasal, oral, and tracheal suctioning and injections. The study examined the effects on the child's behavior when a visual and auditory stimulus was provided to warn the child when an invasive procedure was going to occur. This helped the child learn to discriminate "unsafe" periods when painful or otherwise distressing procedures would occur from the much

longer duration "safe" periods when no warning signal or aversive procedures would occur. The signal was provided by a box containing a red light and a low buzzer that was attached to the child's crib. The signal was activated by the medical staff using a push-button switch immediately before and during the performance of every invasive procedure and turned off immediately after the procedure was completed. The child was observed directly one to three times per day across all shifts seven days a week, and the signal box was provided and withdrawn according to an A-B-A-B treatment withdrawal experimental design. The results showed that when the child had a way to differentiate between aversive procedures and safe periods, more positive mood and behavior was observed along with less negative behavior such as crying.

Despite the demonstrated effectiveness of the behavioral interventions described above, few studies have addressed the behavioral distress of children with IDD during needle sticks or painful medical procedures. A notable exception is a study that employed stimulus fading and gradual exposure combined with differential reinforcement to manage the behavioral distress of an adolescent with needle phobia, autism, mental retardation, and type 2 diabetes.[82] The patient had a history of noncompliance during blood draws to test his glucose levels. The authors employed an A-B-A-B reversal design to test the effects of the intervention. During baseline assessments, the patient was instructed to place his arm in an outline drawn on poster board as the therapist moved the lancet closer to his index finger. Initially he pulled his arm away whenever an attempt was made to perform a finger prick. Stimulus fading plus differential reinforcement of the absence of avoidance behavior was implemented across intervention trials. Gradually, the patient learned to tolerate the lancet closer and closer to his finger (up to 1cm away). After being able to do this consistently, finger pricks were again attempted and were successful. Later these benefits also carried over to other settings (nurse's station, patient's home) and continued to be successful when conducted again two months later.

A recent study[83] used similar behavioral procedures to teach five boys and one girl with autism spectrum disorders between the ages of 8 and 16 to cooperate with injections for immunizations. In this study, teaching procedures were conducted in the children's school settings. Each participant was gradually exposed to the medical material and sensations involved in an injection according to a task analysis. A mild pinch of the skin and touch with an ice cube were used to simulate the sensation of the needle insertion. The participants received positive reinforcement using coins as

tokens placed on a Velcro board contingent on cooperative behavior. The tokens were immediately exchanged for preferred backup reinforcers after the training session, if the participants' performance was cooperative and successful. When necessary, one of the trainers used manual guidance to prevent the participant from standing up or leaving the area until all the tasks for the session were completed correctly (escape extinction). If a participant made any errors on a task or step, he or she continued to rehearse that step until able to perform unprompted and correctly on three consecutive trials. After achieving this criterion, the participant advanced to training on the next step in the task analysis.

Generalization assessments were conducted to demonstrate that the participants' cooperation and skills transferred to different trainers who played the role of the medical practitioner, transferred to other settings, and generalized to the medical practitioner completing the participants' actual injections. Following the research study, additional sessions were conducted to gradually transfer the role of the trainer to the participants' parents, first during practice sessions with mock injections and ultimately during actual medical appointments for injections. In this study the participants received between 74 and 106 training sessions. This number of sessions was possible because the intervention was implemented in the setting where the children went to school every day. To put this study into perspective, the authors noted that "although the participants . . . displayed a range of academic, language and social skills and diverse behavior problems, all were under good instructional control in their classrooms, all had learned to use token systems, and all had substantial experience with making choices of back-up rewards that were available when tokens were exchanged. Ongoing, intensive behavioral intervention provided an essential backdrop for this study." Finally, it is notable that this study was successfully conducted across two different schools, in two different countries with different cultures. Two cases participated in the United States, and three in Turkey.[83]

Another recent study by the author of this book and his colleagues[15] demonstrated the use of a multicomponent behavioral intervention that combined distraction, exposure therapy, counterconditioning, and topical anesthetic during simulated and actual needle stick procedures with eight children with IDD. The training in this study was conducted during weekly or less frequent outpatient clinic visits. The participants were children and adolescents who were referred because they required needle stick procedures for diagnosis or management of their medical conditions.

They all had experienced several unsuccessful attempts by medical staff to complete these procedures. In each case there had been unsuccessful attempts by nursing or medical staff to manually restrain the child for procedures. Prior to behavioral intervention, these children became distressed in the presence of needles, medical stimuli, and medical staff. They attempted to avoid or escape these situations through unsafe, disruptive behavior.

12.7. CASE EXAMPLES

When assessing the efficacy of the behavioral procedures described in section 12.4, the author and colleagues[15] employed an A-B (assessment-treatment) approach with replication across eight participants, along with a group, pre-post comparison of cooperation and behavioral distress scores. Figure 12.1 displays data for three of the eight participants in the study. The results were similarly positive for all of the participants. Prior to treatment, all of the children exhibited behavioral distress and poor cooperation, preventing safe and successful needle procedures.

After the behavioral interventions were introduced, each patient's behavioral distress decreased markedly, and each successfully cooperated with their mock and actual needle stick procedures. The investigators used paired-samples *t*-test analyses to compare the group means for the initial assessment and the final session (actual needle stick). Based on the results of these analyses, the behavioral interventions resulted in statistically significant increases in cooperation and decreases in behavioral distress. The behavioral intervention required 4–15 sessions lasting 30–60 minutes for each participating child. The results support the effectiveness of behavioral intervention combining exposure therapy during mock needle stick procedures, distraction, counterconditioning, and topical anesthetic (EMLA) to reduce behavioral distress and establish consistent cooperation during mock and actual needle stick procedures in children with autism, pervasive developmental disorder, or attention deficit hyperactivity disorder. All of the participating children previously had been unable to have their procedure completed even when four or more adults had attempted to manually restrain them. Some of the children were months or even years overdue for their prescribed medical testing that required needle sticks.

It cannot be said that the procedures were painless during intervention, but the children appeared calm and distracted by their preferred activities.

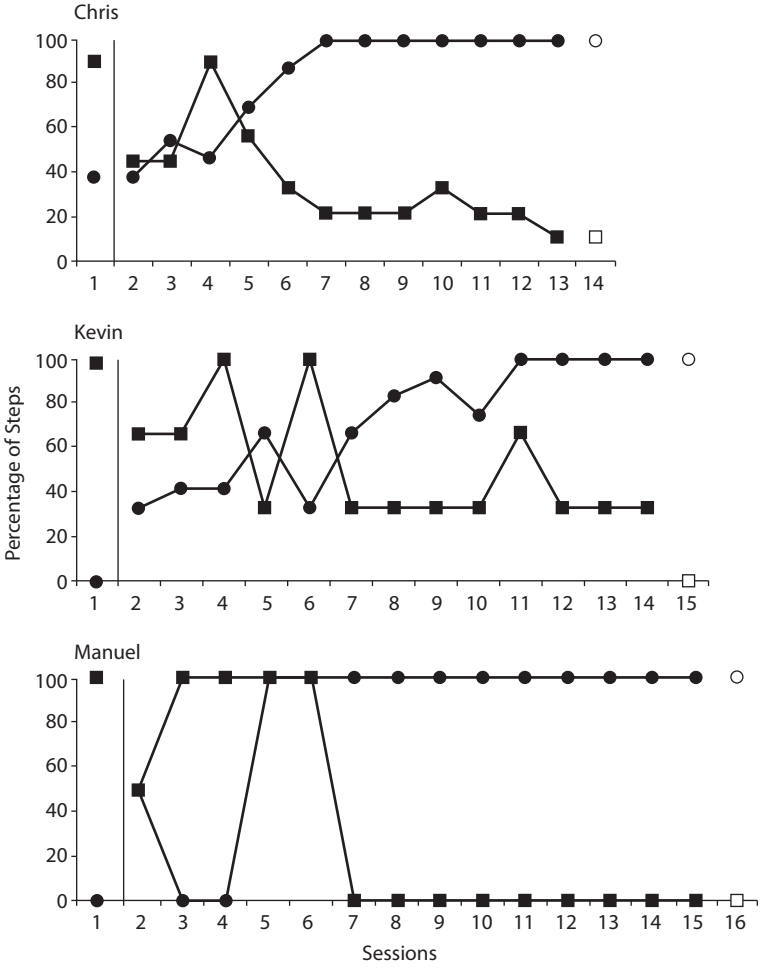

Figure 12.1 Data from three of the eight participants in the Slifer et al. (2011) study. The percentages of task analysis steps with cooperation (*circles*) and behavioral distress (*squares*) are shown across assessment (*before heavy vertical line*) and treatment (*after heavy vertical line*) for Chris, Kevin, and Manuel. The data from these three participants are representative of all eight participants. Mock needle procedures are depicted with filled symbols, and actual needle procedures are depicted with open symbols. *Source*: Slifer, K.J., Hankinson, J.C., Zettler, M.A., et al. (2011). Distraction, exposure therapy, counterconditioning and topical anesthetic for acute pain management during needle sticks in children with intellectual and developmental disabilities. *Clinical Pediatrics*, *50*, 688–697. Reprinted with permission from Sage.

They displayed mainly positive mood and behavior during the mock and actual needle procedures, and they did not require restraint or sedation to complete this routine medical care.

This study had a number of relative limitations. A no-intervention control group was not included, but in keeping with single-subject experimental design methods, each participant served as his or her own control. Behavioral change was analyzed by comparing the data from the initial assessment with subsequent treatment session data, most importantly the sessions in which real needle stick procedures were performed by medical staff. Carefully controlled RCTs are needed to compare a group that receives the combined behavioral and topical anesthetic intervention with a usual care control group in a study enrolling children with a history of severe needle stick–related behavioral distress.

Another limitation, given the design of the study, is that one cannot say for sure that the behavioral intervention and topical anesthetic caused the observed behavior changes. Nevertheless, the similar outcomes across eight cases provide encouraging evidence. Importantly, two participants were successful with their needle stick procedures even without the use of topical anesthetic. This suggests that the behavioral intervention may have been responsible for the behavior changes, and that the topical anesthetic may not be necessary. This is further supported by studies in which some children rate the pain of needle sticks highly even when a topical anesthetic was used.[84-85] Nonetheless, the use of topical anesthetic such as EMLA, tetracaine, or the equivalent is recommended to decrease the probability of needle stick pain.[86-87]

Child maturation over time and habituation to the painful stimulus are alternative explanations for the study results, but they are unlikely given the relatively short interval of time over which the intervention was conducted for these children and the fact that other studies have failed to demonstrate such a habituation effect.

Follow-up component analysis research is needed to identify the parts of the intervention that are necessary for improvements in child cooperation and corresponding reductions in distress and escape/avoidance behavior.

KEY CONCEPTS

- Children with chronic illness require repeated medical procedures that can be painful despite pharmacological interventions.

- From the child's point of view, the painful stimulation is intermittent, unpredictable, and uncontrollable.
- Under these conditions, negative behavior patterns can develop, including conditioned anxiety, physical and social withdrawal, attempts to avoid or escape medical stimuli, and, in some cases, severe tantrums or aggression.
- Behavioral and cognitive-behavioral therapies can provide relief from procedural pain, distress, and anxiety.
- A task analysis of the behavior required to cooperate with a painful procedure and direct observation measurement can be used to assess the child's procedure-related behavior and to monitor progress during intervention.
- Whenever possible, medical, behavioral, and family caregivers should collaborate well in advance of a scheduled procedure concerning what pain and distress management strategies will be used.
- Behavioral interventions based on simple and interactive distraction, exposure therapy, counterconditioning, and teaching and coaching anxiety/pain coping skills during in vivo role playing or mock medical procedures are well supported by the research literature.
- Environmental and behavioral interventions based on principles of aversive conditioning, conditioned anxiety, conditioned suppression, and discrimination learning can be helpful in managing behavioral distress during painful medical procedures.
- With careful planning and interdisciplinary coordination, environmental, behavioral, and cognitive-behavioral interventions can be productively combined with pharmacological interventions such as topical anesthetic and/or antianxiety medication to decrease child behavioral distress during painful medical procedures.
- In nonemergency situations, family caregivers, behavioral therapists, pediatric psychologists, and other allied health professionals can and should advocate for the use of evidence-based environmental, behavioral, and pharmacological interventions to help children learn to cooperate and cope with painful medical procedures without resorting to sedation, general anesthesia, or physical restraint.

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